

# STANDING VOICE

England & Wales · Charity number 1151250

## Details

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**Status** Registered

**Legal form** CIO

**Registered** 2013-03-14

**Register** [View on the Charity Commission register](#)

## Contact

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**Website** [www.standingvoice.org](http://www.standingvoice.org)

## Activities

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**Objects:** THE OBJECTS OF THE CIO ARE, FOR THE PUBLIC BENEFIT THROUGHOUT THE WORLD: (I) THE ADVANCEMENT OF EDUCATION; (II) THE ADVANCEMENT OF MENTAL AND PHYSICAL HEALTH AND THE SAVING OF LIVES; (III) THE RELIEF OF POVERTY AND THE IMPROVEMENT OF THE CONDITIONS OF LIFE IN SOCIALLY AND ECONOMICALLY DISADVANTAGED COMMUNITIES; AND(IV) THE PROMOTION OF HUMAN RIGHTS AND THE PROMOTION OF EQUALITY AND DIVERSITY, IN PARTICULAR BUT WITHOUT LIMITATION SO AS TO RELIEVE THE NEEDS OF PEOPLE WHO ARE SOCIALLY EXCLUDED BY ASSISTING THEM TO INTEGRATE INTO SOCIETY. FOR THE PURPOSES OF THE PRECEDING CLAUSE: (I) HUMAN RIGHTS MEANS HUMAN RIGHTS AS DEFINED IN THE UNIVERSAL DECLARATION OF HUMAN RIGHTS AND SUBSEQUENT UNITED NATIONS CONVENTIONS AND DECLARATIONS AND WILL BE PROMOTED IN PARTICULAR BY EDUCATION ABOUT HUMAN RIGHTS AND PROMOTING RESPECT FOR HUMAN RIGHTS;(II) PEOPLE WHO ARE SOCIALLY EXCLUDED MEANS PEOPLE WHO ARE EXCLUDED FROM SOCIETY, OR PARTS OF SOCIETY, AS A RESULT OF ONE OR MORE OF THE FOLLOWING FACTORS: FINANCIAL HARDSHIP; YOUTH OR OLD AGE; ILL HEALTH (PHYSICAL OR MENTAL); DISABILITY OR MEDICAL CONDITION; DISCRIMINATION ON THE GROUNDS OF SEX, RACE, ETHNIC ORIGIN, RELIGION, COLOUR, CREED OR SEXUALITY; POOR EDUCATION OR SKILLS ATTAINMENT

**Activities:** Standing Voice's objective is to end human rights violations against marginalised groups through its Education, Health, Advocacy and Community Programmes. We currently focus on promoting the social inclusion of people with albinism in Africa, who commonly face extreme social exclusion leading to

marginalisation from health and education services, social support, and witchcraft-fuelled murder.

## Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Other Finance, Provides Human Resources, Provides Buildings/facilities/open Space, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body, Other Charitable Activities
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability, The Prevention Or Relief Of Poverty, Overseas Aid/famine Relief, Accommodation/housing, Arts/culture/heritage/science, Economic/community Development/employment, Human Rights/religious Or Racial Harmony/equality Or Diversity
- **Who:** Children/young People, People With Disabilities, Other Charities Or Voluntary Bodies, Other Defined Groups, The General Public/mankind

## Geography

- Malawi
- Tanzania

## Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£1,427,928	£1,269,270	£718,126	5
2023-12-31	£1,192,750	£1,070,753	£559,467	6
2022-12-31	£911,951	£777,946	£437,470	6
2021-12-31	£446,643	£563,174	-	-
2020-12-31	£498,154	£487,778	-	-

## Trustees

Name	Role	Appointed
Sabine Zetteler	Chair	2014-02-07
Gurmeet Kaur		2016-07-26
HARRY FREELAND		2013-03-08
Innocentia Nobuhle Mgjijima-Konopi		2022-01-03
JONATHAN BEALE		2025-12-19

**STANDING VOICE**

England & Wales - Charity number 1151250

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# Accounts

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# Annual Report and Accounts **2024**



Registered with  
**FUNDRAISING  
REGULATOR**

Registered charity  
No.1151250

## FOREWORD

2024 has been a defining chapter in the evolution of Standing Voice, a year in which ambition met action, and our programmes grew in impact, integration, and scale. Across Tanzania and Malawi, we expanded our reach while tackling the systemic barriers faced by people with albinism. At the centre of this transformation is a simple but powerful truth: health, education, protection, and dignity are not separate needs, they are interconnected rights. This year, we invested in making those connections stronger than ever. By interlinking our programmes more intentionally, we've ensured that every point of engagement, whether a clinic visit, a call to our helpline, or a meeting with a trained teacher, can open the door to a wider system of care and support.

Our Skin Cancer Prevention Programme (SCPP) continued to serve as a cornerstone of this work. Now reaching 12,159 individuals through 278 health centres, it is the largest initiative of its kind for people with albinism on the continent. In 2024, we advanced its long-term sustainability, strengthening the foundation for national coverage in both Tanzania and Malawi by 2027, thanks to the continued support of the Pierre Fabre Foundation, the European Union, and our new three-year partnership with the Croda Foundation.

Meanwhile, our Vision and Education Programme (VEP) accelerated its expansion across Tanzania and launched in Malawi for the first time. Thousands accessed specialist low-vision care and assistive devices, while our teacher training initiative equipped educators with the knowledge and confidence to support inclusive education. From classrooms to clinics, this work is enabling children with albinism not only to participate, but to thrive.

Beyond health and education, our Welfare and Social Protection Programme continued to address the ongoing risks of violence, stigma, and exclusion. In 2024, we provided tailored support to survivors, including medical care, counselling, and safer housing, while strengthening peer-led services through partners like the Mothers' Albinism Action Group. With support from the Evans Cornish Foundation and C-Sema, we launched our first call centre in Mwanza and developed a CRM system to improve helpline response and referrals across both countries.

All of this progress has been made possible through the continued support of our valued funding partners. We are deeply grateful to those who have stood beside us year after year, and to those who joined our mission for the first time in 2024. Our sincere thanks go to: the Pierre Fabre Foundation, European Commission, the Croda Foundation, the United Nations Voluntary Fund for Victims of Torture, the International League of Dermatological Societies, the International Foundation for Dermatology, the Bilton Charitable Foundation, the John Armitage Charitable Trust, Inside the Same, Deloitte Community Fund, The HCD Memorial Fund, the Irish Global Health Network, Global Skin, Global Green Grants, the Souter Charitable Trust, the Evans Cornish Foundation, the Reed Foundation, Manuli Ryco, Altruist, African Albinism Foundation, Glasgow University, and Cambridge University. We also acknowledge the many funders and allies who prefer to remain anonymous, your impact is visible and deeply valued. We also offer our heartfelt thanks to our staff, partners, and the communities we serve. Your resilience, insight, and determination inspire us every day. Together, we are not only responding to today's urgent needs, we are building structures of care, equity, and justice that will last.

Finally, we wish to extend our deepest gratitude to Jon Beale, who in September 2024, after 13 years of exceptional service, stepped down from the Standing Voice staff team. As a founding member, Jon's vision, compassion, and tireless commitment have shaped the heart and soul of this organisation. While his daily presence will be greatly missed, we are delighted he will be joining the UK Board as a trustee, continuing to guide the mission he helped build.

As we look to the future, our vision is clear: a world in which the rights of people with albinism are recognised without exception, where inclusion is a lived reality, and where no one is left behind.

With gratitude,



**Sabine Zetteler**

*Chair of the Board of Trustees*

28/04/2024

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## 1. LEGAL AND ADMINISTRATIVE INFORMATION

<i>Charity Name</i>	Standing Voice (UK)
<i>Charity No.</i>	No. 1151250 Charitable Incorporated Organisation (CIO)
<i>Administrative offices</i>	<p>Standing Voice UK          Unit 34b          Regent Studios          8 Andrews Road          London          E8 4QN</p> <p>Standing Voice Tanzania          P.O. BOX 1902          Isamilo, Mwanza          Tanzania</p> <p>Standing Voice Malawi          Area 14          Plot No.63          Lilongwe</p>
<i>Registered Addresses</i>	<p>49 Newick Road          London          E5 0RP</p> <p>P.O. BOX 180          Ukerewe Island, Mwanza          Tanzania</p> <p>Area 14          Plot No.63          Lilongwe</p>
<i>UK Board of Trustees</i>	Sabine Zetteler (Chair) Gurmeet Kaur (Treasurer) Innocentia Magijima Harry Freeland
<i>Malawi Board of Trustees</i>	Grace Malera Tadala Chinkwezule Jonathan Beale
<i>Tanzania Board of Trustees</i>	Katwale Magaga Ally Possi Martha Mganga Harry Freeland
<i>UK Administration</i>	Harry Freeland, Jonathan Beale, Alfred Thomas Giovanna Giuriolo, Ruth Ayarza. Supported by A team of dedicated volunteers

## 2. REPORT OF THE TRUSTEES

### 2.1 Constitution

Standing Voice (UK) was originally constituted under a Foundation Constitution that came into effect on 14th March 2013, on which date Standing Voice became registered as a Charitable Incorporated Organisation (CIO). The trustees are the only members of the CIO. If the CIO is wound up the members have no liability to contribute to its assets and no personal responsibility for settling its debts or liabilities.

### 2.2 Board of Trustees

Trustees are appointed by existing trustees through an electoral process. There may be no fewer than three trustees at any one time on the Board of Trustees. There are four at present, and we aim to expand the Board further during 2024.

Standing Voice trustees hold quarterly board meetings. The board also addresses governance matters as and when necessary, through e-mail or other means as necessary.

Decisions are made either at a meeting of the charity trustees, by resolution in writing or electronic form and agreed upon by all of the charity trustees. Agreements may comprise either a single document, or several documents containing the text of the resolution in like form to each of which one or more charity trustees has signified their agreement.

No decision shall be made at a trustee meeting unless a quorum is present at the time the decision is taken. The quorum is two charity trustees, or the number nearest to one third of the total number of charity trustees, whichever is greater, or such larger number as the charity trustees may decide from time to time.

In selecting trustees, consideration is given to the overall breadth of knowledge and experience required of the Board of Trustees. Candidates are typically interviewed by at least two existing trustees and nominations are then presented for approval to the board. Successful candidates, once appointed, receive appropriate documentation about the roles and responsibilities of being a Standing Voice trustee.

Standing Voice has three international boards: Standing Voice UK (4 members), Standing Voice Tanzania (4 members) and Standing Voice Malawi (3 members).

### 2.3 Advisory Board

The Standing Voice Board of Trustees is supported by an Advisory Board made up of 9 experts from 7 countries (Malawi, Tanzania, Togo, USA, UK, France and Ireland). This includes a wide range of expertise in the fields of public health, dermatology, ophthalmology, education, trauma recovery, genetics, general medicine and surgery, and in-depth knowledge on albinism.

The Advisory Board provides expert guidance to the UK Board of Trustees and staff management team, by advising on strategy, and informing the design and implementation of our programmes. The Advisory Board also works closely with Standing Voice's wider staff teams, with a primary focus on developing resources and training manuals, leading the delivery of clinical and surgical training, conducting research and publication, and identifying funding opportunities.

Our warmest thanks go to our Advisory Board; Our current Chair of the Board Dr Andrew Sharp, and members; Professor Daudi Mavura, Dr Kelvin Maponda, Professor Melissa Levin, Dr Mark Wheeler, Professor Bayaki Saka, Dr Patricia Lund, Professor Charlotte Baker and Mark Fish.



## 2.4 Organisational Structure

The UK Board of Trustees governs Standing Voice on a voluntary basis, meeting quarterly or as needed. As Standing Voice Malawi and Tanzania report to the UK entity, the UK Board holds primary governance responsibility for the organisation's global operations. Trustees bring diverse expertise spanning international development, human rights, financial management, media, public relations, and the arts.

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Standing Voice maintains registered offices in both Malawi and Tanzania, each overseen by a local Board of Trustees. These boards ensure compliance with local governance standards and bring together professionals in law, human rights, organisational management, and national human rights institutions. Day-to-day leadership of our country teams is provided by the Executive Director in Malawi and Operations Director in Tanzania.

Harry Freeland has served as Executive Director of Standing Voice UK since April 2014 and sits on both the UK and Tanzania Boards of Trustees. During the reporting period, the UK team included five paid staff, supported by a dedicated group of volunteers. Globally, Standing Voice's team includes 22 staff in Tanzania and 12 in Malawi, bringing the total international staff to 39.

People with albinism and their families are central to Standing Voice's leadership and decision-making structures. They are represented as trustees and senior leaders across our offices in the UK, Malawi, and Tanzania, ensuring that our governance, programmes, and fundraising remain grounded in lived experience and accountable to the communities we serve.

## 2.5 Contributions of Volunteers

Standing Voice continues to benefit from the invaluable contributions of skilled volunteers from a wide range of professional and academic backgrounds, all united by a commitment to improving the health and wellbeing of persons with albinism Africa.

Throughout the reporting period, our programmes have been strengthened by a network of dedicated local and international volunteers, including researchers, academics, ophthalmologists, dermatologists, surgeons, psychotherapists, geneticists, tailors, and performance artists. These experts have played a critical role in advancing our work by contributing to research, developing educational resources, delivering training, and offering ongoing mentorship to our teams.

This collective engagement has fostered a unique and growing pool of specialised knowledge on albinism that supports our global operations. To formalise and sustain this expertise, we have established an advisory board that works closely with our staff teams, providing strategic guidance and specialist input.

We are deeply grateful to all the volunteers who have generously shared their time, skills, and insight in 2024, helping to shape and expand the reach, quality, and impact of our life-saving programmes.

While there are too many to name individually, volunteer highlights in 2024 included impactful training in Neno and Mwanza districts of Malawi, delivered by Irish volunteers and Advisory Board members Dr. Mark Wheeler and Carol O'Dea, who provided essential capacity building to local clinical teams. We also continued our close collaboration in Malawi with UK-based psychotherapist and trauma specialist Mark Fish, who has been instrumental in developing a system of support for the mental health and wellbeing of individuals impacted by albinism-related trauma. In Tanzania, clinical and surgical training was led by Dr. Andrew Sharp, Mohs Surgeon and Chair of the SV Advisory Board, in partnership with Consultant Dermatologists Dr. Elizabeth Roberts and Dr. Emily Twigg from Leicester Royal Infirmary.

Ongoing oversight of our Vision and Education Programme was provided by Dr. Rebecca Kammer, a US-based optometrist and internationally recognised albinism specialist, working in close partnership with Tanzania-based optometrist and Vision Programme leader Abdy Nyembo.



*A team of volunteer trainers, trainees and partners from the Pierre Fabre Foundation during a Clinical Training Workshop held in Mwanza in August 2024*

## 2.6 Our Purpose and Objectives

Standing Voice is an international NGO working in Tanzania and Malawi, with its headquarters in the United Kingdom. Standing Voice's primary objective is to improve the quality of life of people with albinism in Africa.

The objectives of the CIO are:

- I.** the advancement of education;
- II.** the advancement of mental and physical health and the saving of lives;
- III.** the relief of poverty and the improvement of the conditions of life in socially and economically disadvantaged communities;
- IV.** the promotion of human rights and the promotion of equality and diversity, in particular but without limitation so as to relieve the needs of people who are socially excluded by assisting them to integrate into society.

For the purposes of the above:

**I.** "human rights" means human rights as defined in the Universal Declaration of Human Rights and subsequent United Nations conventions and declarations and will be promoted in particular by education about human rights and promoting respect for human rights;

**II.** people who are "socially excluded" means people who are excluded from society, or parts of society, as a result of one or more of the following factors: financial hardship; youth or old age; ill health (physical or mental); disability or medical condition; discrimination on the grounds of sex, race, ethnic origin, religion, colour, creed or sexuality; poor education or skills attainment.

Standing Voice exists as a catalyst to amplify the voices of others. We aim to empower the people we work with to be the agents of change in their own lives, to build resilience and be healthy and self-sufficient. We currently focus on promoting the social inclusion of people with albinism in Tanzania and Malawi, whilst building the capacity of human rights defenders and partners in other countries in the region. Our team has over 19 years' experience working with this group and has pioneered innovative models of working that have a proven record of replication and scalability.

People with albinism are commonly the victims of social exclusion in Sub-Saharan Africa, which has led to witchcraft-fuelled murder and marginalisation from health and education services. Our work with this group centres around several programmatic areas: Skin Cancer Prevention, Low Vision and Education, Trauma Recovery, Economic Empowerment and Advocacy. Through our core programmes our support is holistic and comprehensive to reflect the complex needs of people with albinism in their local context. We achieve our objectives by collaborating with a network of local stakeholders (such as government bodies, local community groups and NGOs). All of our initiatives promote the social inclusion of people with albinism by:

- I.** Advancing understanding and knowledge about albinism in wider society
- II.** Advocating for progressive state action
- III.** Developing the skills and expertise of both people with albinism and wider community members
- IV.** Increasing the positive impact of local service providers
- V.** Promoting the positive impact of local non-governmental stakeholders (civil society)

The trustees of Standing Voice declare that they have had regard to both the Charity Commission guidance on public benefit and section 17(5) of the Charities Act 2011 on public benefit in carrying out their duties to achieve the charity's objectives.

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### 3. PRINCIPAL ACTIVITIES

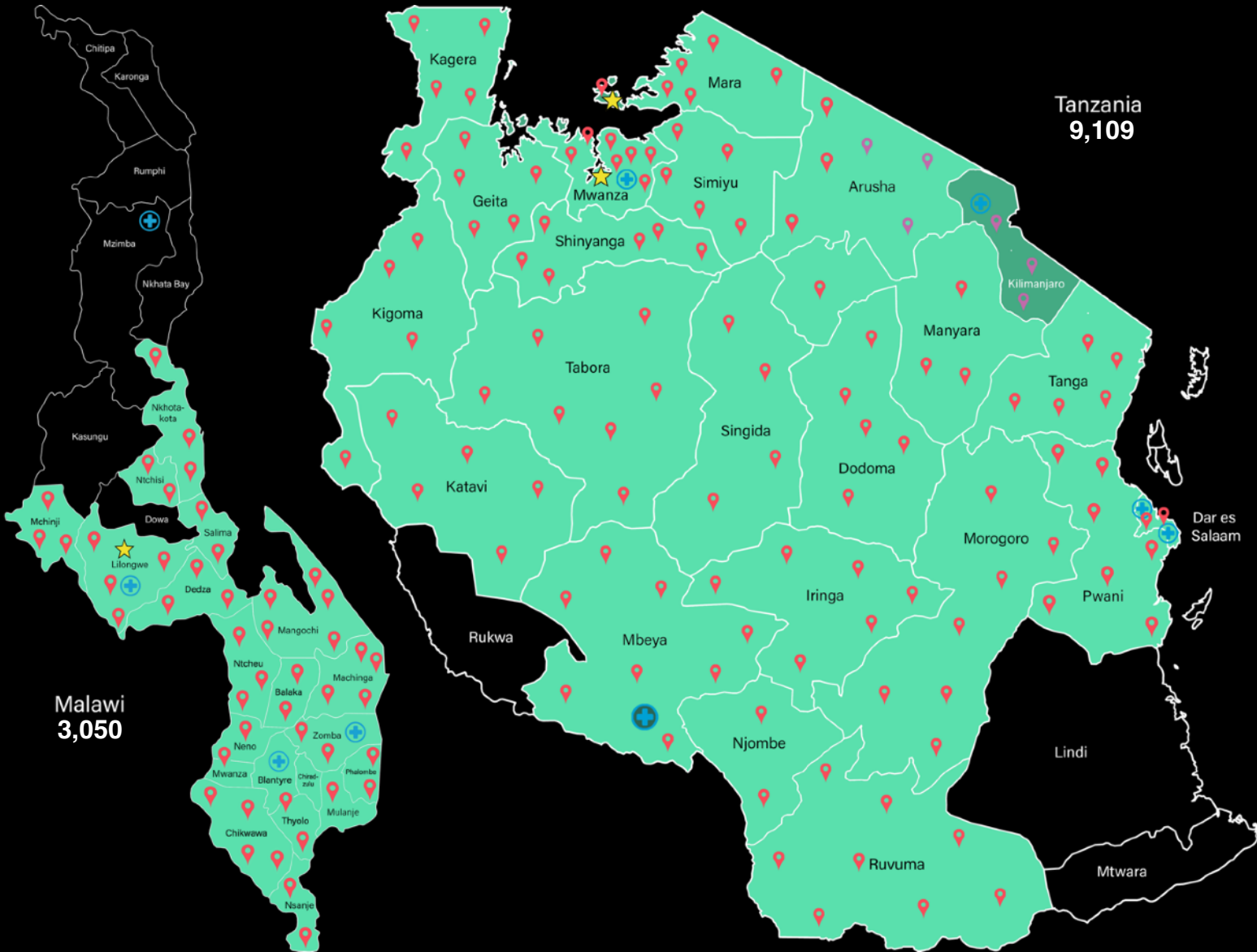
In 2024, Standing Voice delivered a range of integrated programmes aimed at advancing the rights and wellbeing of persons with albinism across Tanzania and Malawi. Our interventions focused on improving access to inclusive healthcare, quality education, sustainable livelihoods, psychosocial support, and trauma-informed care, ensuring that individuals with albinism can live with dignity, safety, and opportunity.

Across all programme areas, we directly reached 12,159 individuals with albinism and engaged thousands more through community outreach, training, and advocacy campaigns, building broader societal awareness and challenging the stigma, discrimination, and systemic exclusion faced by this population.










# Geographical reach (Dec 2024)

Total people with albinism served through all programmes: 12,159



## Current SCPP Operations

-  Skin Cancer Prevention Programme
-  RDTC DVO training region
-  Regions currently not served
-  Standing Voice Offices
-  Referral Hospitals
-  Clinics coordinated by Standing Voice
-  Clinics coordinated by the RDTC

### 3.2 Demographic Breakdown - all programmes

	Tanzania		Malawi	
	Number	%	Number	%
<b>Total registered clients (across all programs)</b>	9,109		3,050	
<b>Female</b>	4,669	51.2%	1,539	50.1%
<b>Male</b>	4,440	48.8%	1,511	49.9%
<b>Average age</b>	18		17	
<b>0-4</b>	1,784	19.6%	667	21.9%
<b>5-9</b>	1,567	17.2%	474	15.5%
<b>10-14</b>	1305	14.3%	457	15.0%
<b>15-19</b>	1265	13.9%	416	13.6%
<b>20-24</b>	805	8.8%	301	9.9%
<b>25-29</b>	598	6.6%	233	7.6%
<b>30-34</b>	473	5.2%	149	4.9%
<b>35-39</b>	399	4.4%	131	4.3%
<b>40-44</b>	289	3.2%	87	2.9%
<b>45-49</b>	221	2.4%	58	1.9%
<b>50-54</b>	154	1.7%	35	1.1%
<b>55-59</b>	89	1.0%	15	0.5%
<b>60-64</b>	78	0.9%	18	0.6%
<b>65-69</b>	41	0.5%	12	0.4%
<b>70-74</b>	18	0.2%	3	0.1%
<b>75-79</b>	8	0.09%	4	0.1%
<b>80 &gt;</b>	14	0.2%	0	0%

#### Patient Demographics: Gender and Age Distribution

We are encouraged to observe continued gender parity within our patient population. In Tanzania, women and men represent 51.2% and 48.8% of all registered patients, respectively. In Malawi, the distribution is similarly balanced, with 50.1% women and 49.9% men.

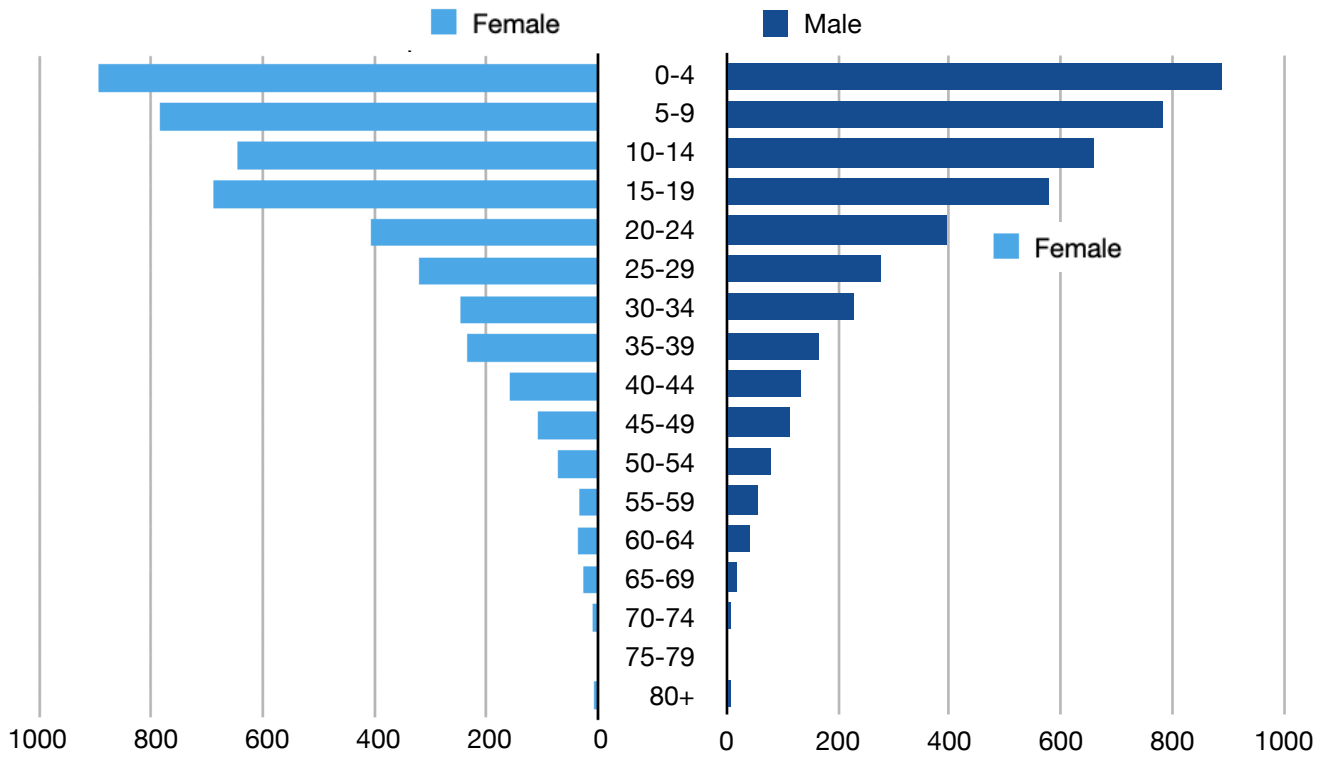
Our patient base continues to be dominated by younger age groups, reflecting the broader age structure of the general population in both countries. The average age of registered patients is 18 years in Tanzania and 17 years in Malawi. Notably, 65.0% of patients in Tanzania and 66.0% in Malawi are aged 19 or below.

Across both countries, 9,872 people, representing 85.1% of the total registered population are under the age of 30, with 65.5% aged 19 or younger. By contrast, only 9.7% of people are over 40, and just 4.0% are over 50. This sharp decline in representation among older age groups reflects both the elevated risk of early mortality from skin cancer among persons with albinism and the overall youthful demographic we serve.

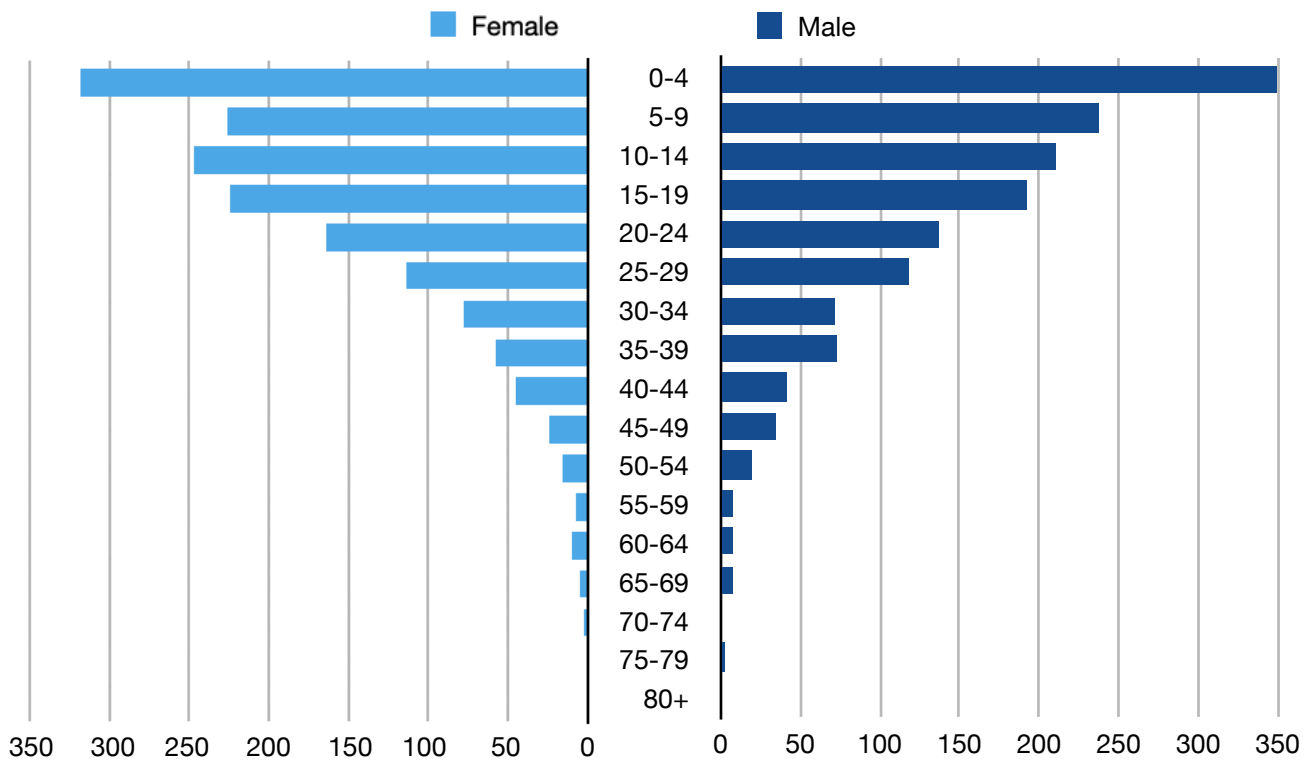
This trend is particularly stark in Malawi, where only 7.6% of the entire population of persons with albinism registered in the SSCP are over the age of 40.

The population pyramids below further illustrate this age distribution, clearly showing the predominance of younger individuals in our registered patient community in both Tanzania and Malawi.

**Distribution of Registered Patients in Tanzania**



**Distribution of Registered Patients in Malawi**



## 4. SKIN CANCER PREVENTION PROGRAMME

### 4.1 Reach and Growth

To confront the skin cancer crisis faced by people with albinism in Africa, Standing Voice launched its Skin Cancer Prevention Programme (SCPP) in 2013. Today, this growing network of dermatology clinics is reaching 11,598 people with albinism (PWA) throughout Tanzania and Malawi. Declared best practice by the United Nations in 2017, this programme is delivered in partnership with the Governments of Tanzania and Malawi, and is supported by over 2,000 health professionals and civil society actors. Through the support and close collaboration of the Pierre Fabre Foundation, European Commission, Croda Foundation and International League of Dermatology Societies we have been able to expand the SCPP at scale, transforming it into the largest skin cancer prevention programme for people with albinism globally.

Each clinic provides health education, skin examination, cryotherapy, and referral for surgery if required. Patients also receive sunglasses, locally made sun hats and a fresh supply of sunscreen at every clinic. Our objective is to support governments and civil society to build national programmes of skin cancer prevention that reach every region and serve the total population of people with albinism.

During 2024 we expanded the SCPP into two new regions of Tanzania and two new districts of Malawi. We conducted mapping exercises, training and engagement meetings with govt and civil society to ensure the full mobilisation of PWA and their duty bearers in the delivery of the SCPP, and we continued to deliver training to health professionals and community advocates, who lead the programme's expansion across both countries. We have seen significant growth in the number of patients enrolled across all programme areas, and we are on track for the SCPP to achieve national coverage of both Tanzania and Malawi by the end of 2027.

Indicator	Tanzania			Malawi		
	Target	Achieved	Difference	Target	Achieved	Difference
<b>Nb regions/districts covered by SCPP</b>	21	21	0	18	19	1
<b>Nb clinic sites</b>	132	142	10	59	136	77
<b>Nb clinics delivered during reporting period</b>	264	268	4	119	258	139
<b>Nb patients registered in SCPP</b>	5,940	8,548	2,608	2,160	3,050	890
<b>Nb patients seen in this period</b>	5,940	6,126	186	2,160	2,372	212
<b>New patients seen in this period</b>	810	1,203	393	240	488	248

By the end of 2024, the SCPP had exceeded or met all our targets regarding patient reach and geographical coverage. The programme had registered 11,598 persons with albinism across Tanzania and Malawi, surpassing our combined target of 8,100 patients for both countries by a margin of 30.2%. This includes 8,548 people enrolled in Tanzania and 3,050 people in Malawi.

21 regions of Tanzania were reached during this reporting period (meeting our target of 21 for the end of 2024), while 19 districts of Malawi were reached (surpassing our target of 18 districts). This means that today the SCPP is operational in 67.4% of all regions in Tanzania (21 of 31), and 67.9% coverage of all districts in Malawi (19 of 28). Clinics are now active in 278 hospitals and health centres across both countries. 142 of these facilities are in Tanzania, and 136 are in Malawi. A total of 526 clinics were delivered across both countries during the reporting period. 268 of these were in Tanzania and 258 in Malawi. Since July 2021 and the start of the phase II partnership with the Foundation Pierre Fabre, 1,361 clinics have been delivered across Tanzania and Malawi.

Across the entire year we welcomed a total of 1,691 newly registered patients across both countries, reflecting a combined annual growth rate of 19.8%. This included 1,203 new patients registered in Tanzania (a growth rate of 16.4% from 2023). In Malawi, we saw 488 new patients in 2024 (a growth rate of 19% from 2023).



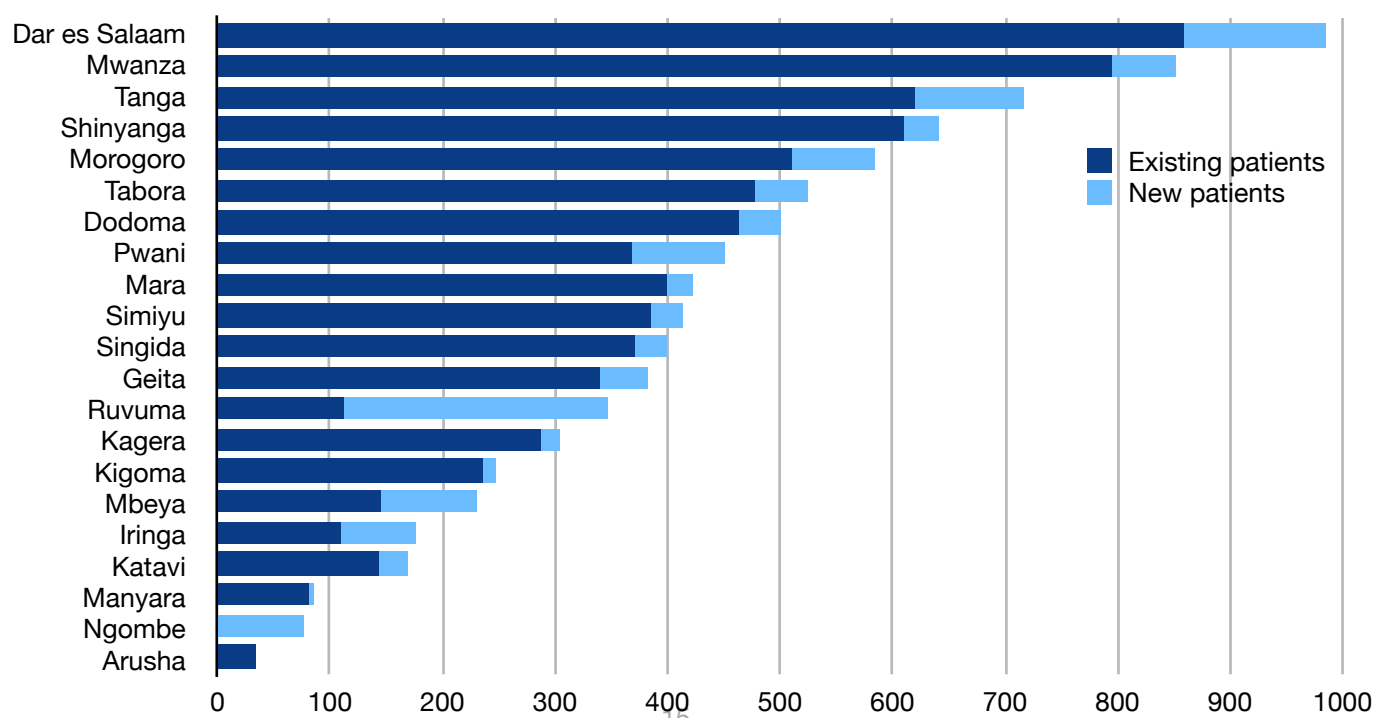
UFULU  
WANGA



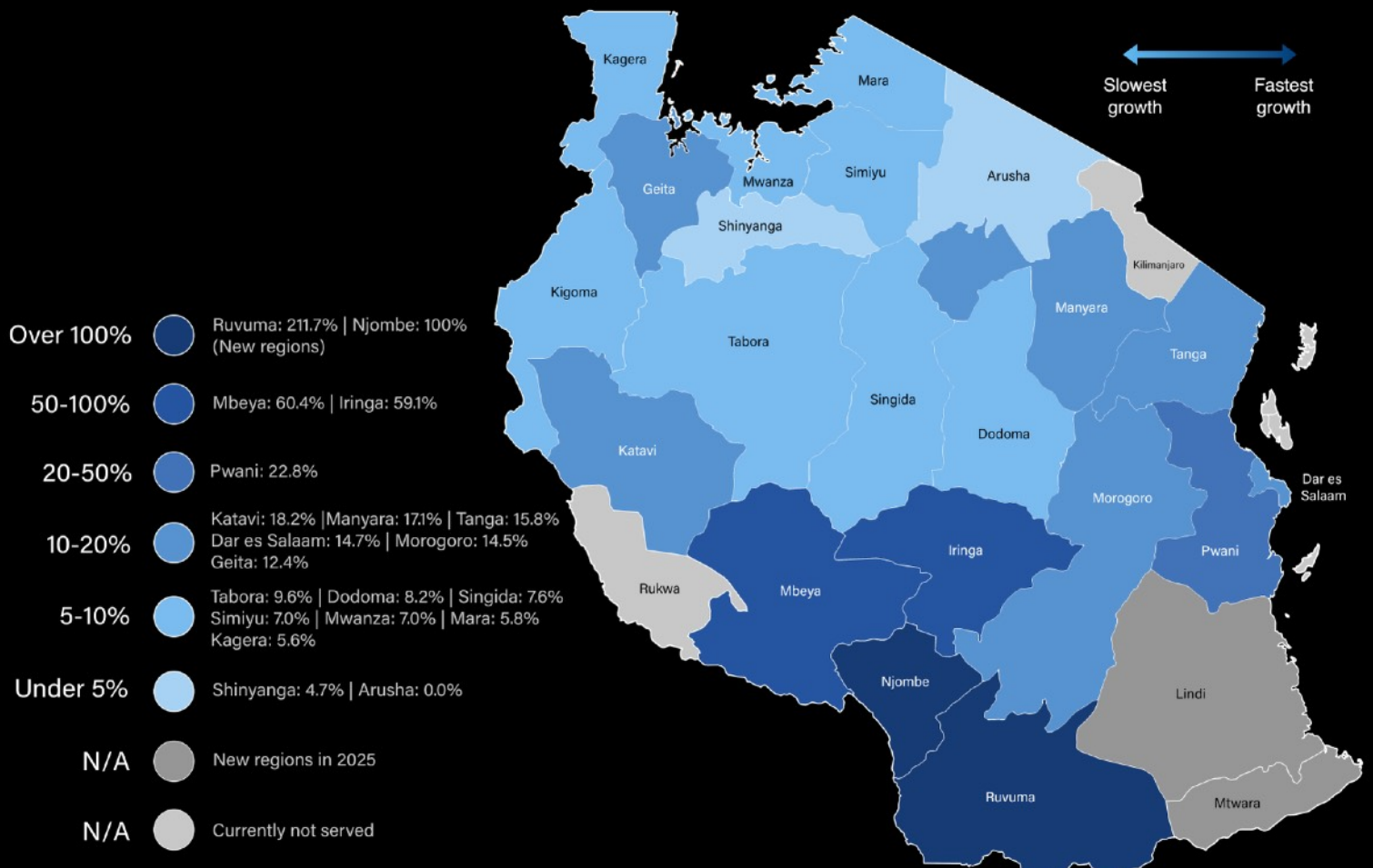
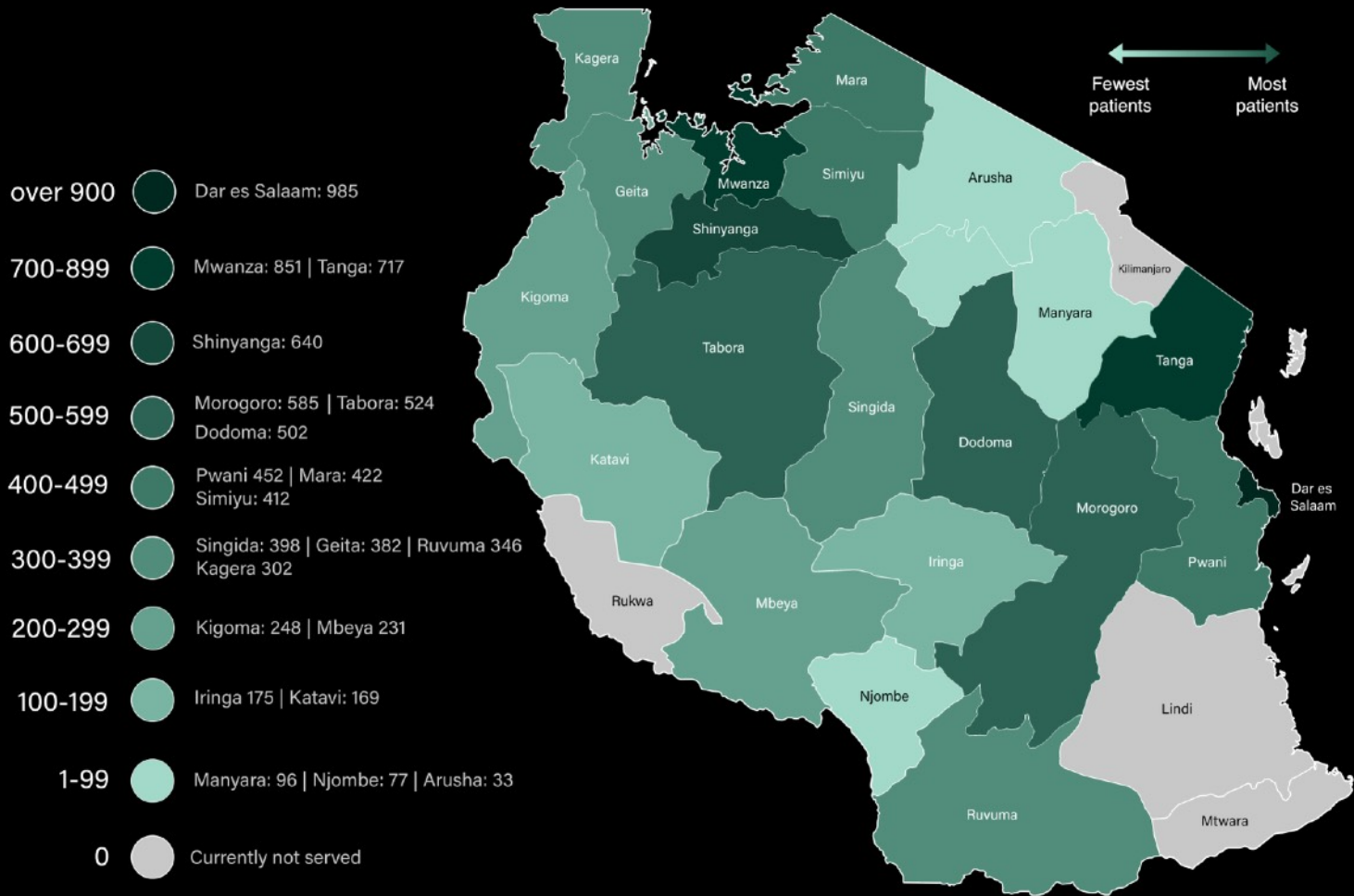
## 4.2 Geographic Breakdown SCPP

TANZANIA	Registered Patients - Disaggregated by Region, Gender, and New/Existing												
	Region	Existing patients			New patients						Total patients		
		M	F	Total	M	Growth in M (%)	F	Growth in F (%)	Total	Total Growth (%)	M	F	Total
<b>Dodoma</b>	245	219	464	18	7.3%	20	12.3%	38	<b>8.2%</b>	263	239	502	
<b>Katavi</b>	59	84	143	15	25.4%	11	13.1%	26	<b>18.2%</b>	74	95	169	
<b>Tabora</b>	227	251	478	20	8.8%	26	10.4%	46	<b>9.6%</b>	247	277	524	
<b>Geita</b>	172	168	340	17	9.9%	25	14.9%	42	<b>12.4%</b>	189	193	382	
<b>Singida</b>	150	220	370	23	15.3%	5	2.3%	28	<b>7.6%</b>	173	225	398	
<b>Mara</b>	188	211	399	9	4.8%	14	6.6%	23	<b>5.8%</b>	188	211	422	
<b>Simiyu</b>	216	169	385	12	5.6%	15	8.9%	27	<b>7.0%</b>	228	184	412	
<b>Kagera</b>	145	142	287	9	6.2%	7	4.9%	16	<b>5.6%</b>	154	149	303	
<b>Kigoma</b>	123	113	236	6	4.9%	6	5.3%	12	<b>5.1%</b>	129	119	248	
<b>Mwanza</b>	376	419	795	30	8.0%	26	6.2%	56	<b>7.0%</b>	406	445	851	
<b>Shinyanga</b>	339	272	611	15	4.4%	14	5.1%	29	<b>4.7%</b>	354	286	640	
<b>Dar es Salaam</b>	406	453	859	62	15.3%	64	14.1%	126	<b>14.7%</b>	468	517	985	
<b>Tanga</b>	288	331	619	39	13.5%	59	17.8%	98	<b>15.8%</b>	327	390	717	
<b>Arusha</b>	12	21	33	0	N/A	0	N/A	0	<b>0.0%</b>	12	21	33	
<b>Manyara</b>	42	40	82	5	11.9%	9	22.5%	14	<b>17.1%</b>	47	49	96	
<b>Morogoro</b>	257	254	511	36	14.0%	38	15.0%	74	<b>14.5%</b>	293	292	585	
<b>Pwani</b>	171	197	368	47	27.5%	37	18.8%	84	<b>22.8%</b>	218	234	452	
<b>Iringa</b>	47	63	110	26	55.3%	39	61.9%	65	<b>59.1%</b>	73	102	175	
<b>Mbeya</b>	75	69	144	46	61.3%	41	59.4%	87	<b>60.4%</b>	121	110	231	
<b>Ruvuma</b>	42	69	111	121	288.1	114	165.2%	235	<b>211.7%</b>	163	183	346	
<b>Ngombe</b>	0	0	0	35	100%	42	100%	77	<b>N/A</b>	35	42	77	
<b>Total</b>	<b>3,580</b>	<b>3,765</b>	<b>7,345</b>	<b>591</b>	<b>16.5%</b>	<b>612</b>	<b>16.3%</b>	<b>1,203</b>	<b>16.4%</b>	<b>4,171</b>	<b>4,377</b>	<b>8,548</b>	

Annually, we recorded a 16.5% increase in registered male patients and a 16.3% increase in registered female patients across Tanzania. Our fastest-growing regions were Ruvuma (211%), Mbeya (60.4%), and Iringa (59.1%), all of which are our newest areas of operation. In contrast, the slowest growth was observed in regions where the SCPP has been active the longest: Shinyanga (4.7%), Kigoma (5.1% and 4.9%), Kagera (5.6%), Mara (5.8%), and Mwanza (7%).

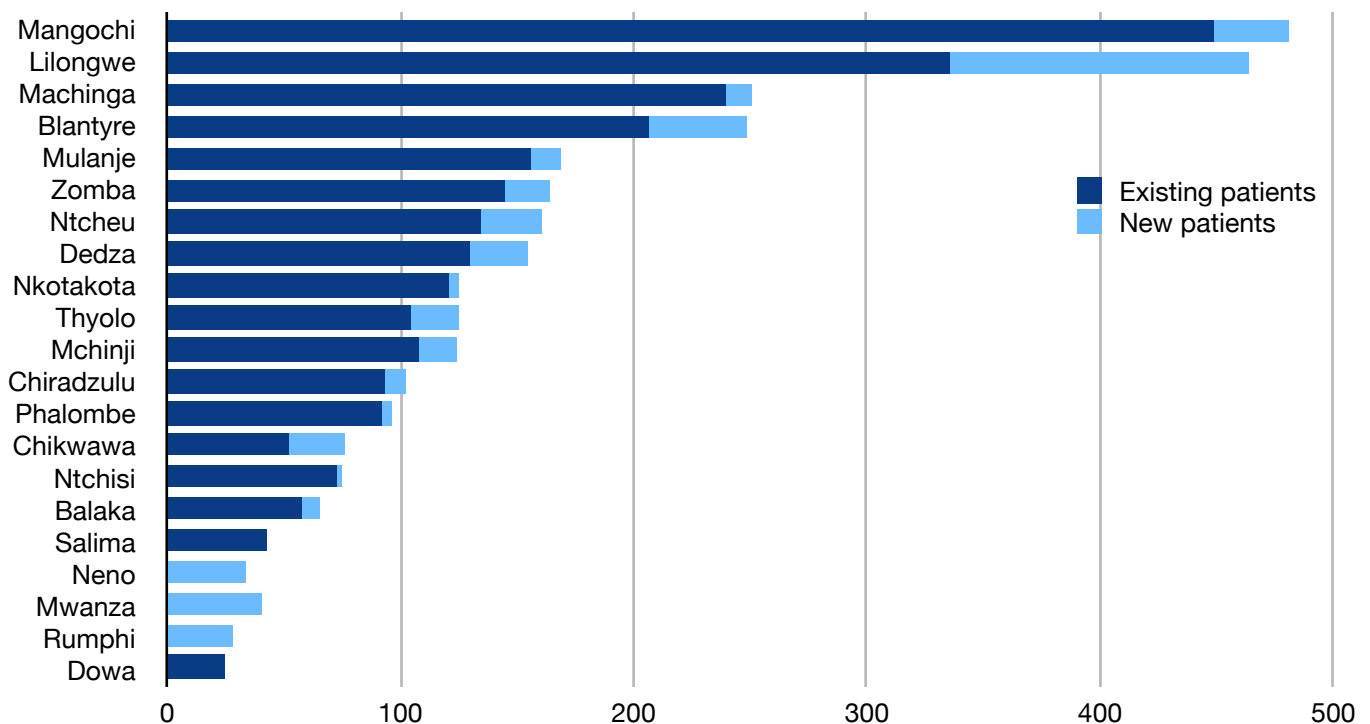


The top map indicates the distributional density of our registered patients in Tanzania: Dar es Salaam has the most registered patients (985) while Arusha has the fewest (33). The bottom map indicates regional growth rates in registered patients: Ruvuma is grew quickest in 2024 (211.7%), while Shinyanga saw the slowest growth (4.7%).

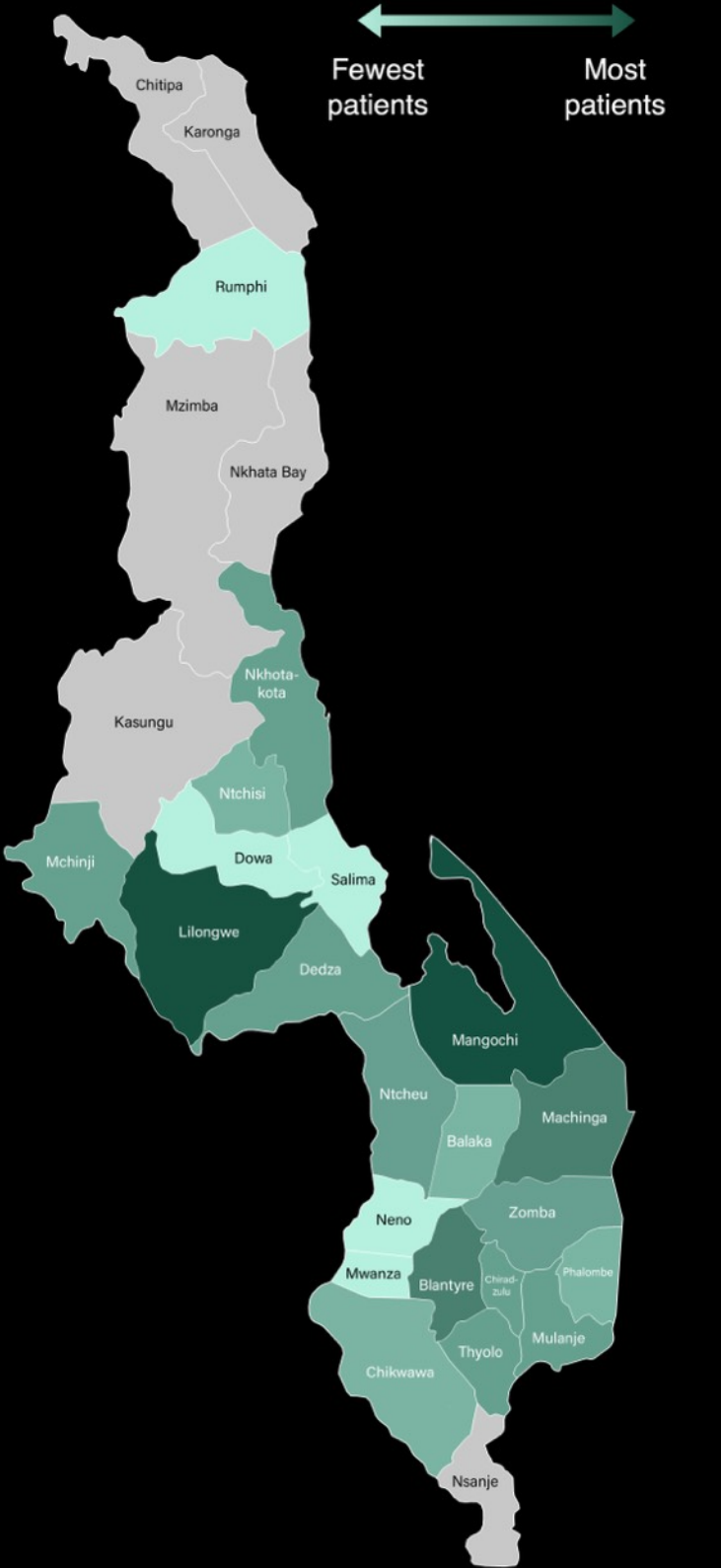


MALAWI	Registered Patients - Disaggregated by Region, Gender, and New/Existing												
	District	Existing patients			New patients						Total patients		
		M	F	Total	M	Growth in M (%)	F	Growth in F (%)	Total	Total Growth (%)	M	F	Total
Machinga	125	114	239	8	6.4%	4	3.5%	12	5.0%	133	118	251	
Mangochi	197	252	449	16	8.1%	16	6.3%	32	7.1%	213	268	481	
Zomba	77	68	145	8	10.4%	11	16.2%	19	13.1%	85	79	164	
Phalombe	43	49	92	1	2.3%	3	6.1%	4	4.3%	44	52	96	
Mulanje	76	80	156	5	6.6%	8	10.0%	13	8.3%	81	88	169	
Balaka	31	27	58	5	16.1%	3	11.1%	8	13.8%	36	30	66	
Dedza	69	61	130	13	18.8%	12	19.7%	25	19.2%	82	73	155	
Ntcheu	71	63	134	15	21.1%	11	17.5%	26	19.4%	86	74	160	
Blantyre	100	106	206	20	20.0%	23	21.7%	43	20.9%	120	129	249	
Mchinji	59	49	108	7	11.9%	9	18.4%	16	14.8%	66	58	124	
Lilongwe	165	171	336	66	40.0%	62	36.3%	128	38.1%	231	233	464	
Chikwawa	25	27	52	14	56.0%	10	37.0%	24	46.2%	39	37	76	
Thyolo	51	53	104	8	15.7%	13	24.5%	21	20.2%	59	66	125	
Chiradzulu	48	45	93	4	8.3%	5	11.1%	9	9.7%	52	50	102	
Salima	27	16	43	0	0%	0	0%	0	0.0%	27	16	43	
Nkotakota	64	57	121	2	3.1%	2	3.5%	4	3.3%	66	59	125	
Ntchisi	39	33	72	0	0.0%	3	9.1%	3	12.5%	39	36	75	
Neno	0	0	0	14	N/A	19	N/A	33	100%	14	19	33	
Mwanza	0	0	0	14	N/A	26	N/A	40	100%	14	26	40	
Rumpi	0	0	0	13	N/A	15	N/A	28	N/A	13	15	28	
Dowa	11	13	24	0	N/A	0	N/A	0	N/A	11	13	24	
<b>Total</b>	<b>1,278</b>	<b>1,284</b>	<b>2,562</b>	<b>233</b>	<b>18.2%</b>	<b>255</b>	<b>19.9%</b>	<b>488</b>	<b>19.0%</b>	<b>1,511</b>	<b>1,539</b>	<b>3,050</b>	

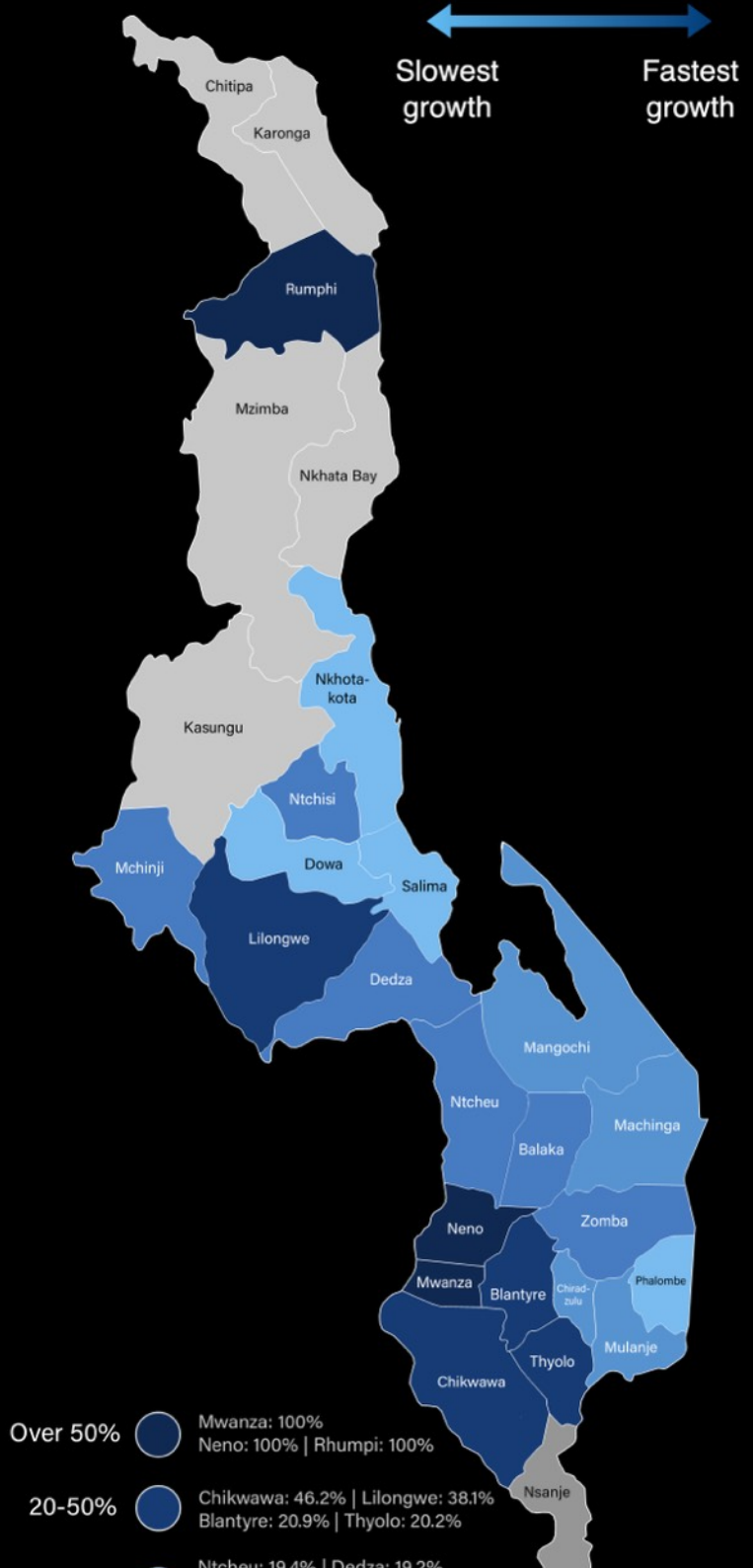
In 2024, we recorded an 18.2% increase in registered male patients and a 19.9% increase in registered female patients in Malawi. The fastest-growing district was Chikwawa, which saw a 46.2% increase, followed by Lilongwe at 38.1%). In contrast, the districts with the slowest growth were Salima, which recorded no increase, Nkhotakota (3.3%) and Phalombe (4.3%). Growth data is not applicable for Neno, Mwanza, as these districts were newly reached in 2024 and therefore do not have a previous baseline. Rumpi and Dowa are also N/A as these locations were reached through International Albinism Awareness Day only.



The map on the left indicates the distributional density of our registered patients in Malawi: Mangochi has the most patients (481) while Salima has the fewest (43). The map on the right indicates district growth rates in registered patients: the fastest growth was in Chikwawa (46.2%), while Salima saw the slowest growth (0%).



- Over 400 ● Mangochi: 481 | Lilongwe: 464
- 200-399 ● Machinga: 251 | Blantyre: 249
- 100-199 ● Mulanje: 169 | Zomba: 164 | Ntcheu: 160 | Dedza: 155  
Thyolo: 125 | Nkhokotakota: 125 | Mchinji: 124 | Chiradzulu: 102
- 50-99 ● Phalombe: 96 | Chikwawa: 76 | Ntchisi: 75  
Balaka: 66
- 1-49 ● Salima: 43 | Mwanza: 40 | Neno: 33 | Rumphi: 28  
Dowa: 24
- 0 ● Currently not served



- Over 50% ● Mwanza: 100%  
Neno: 100% | Rumphi: 100%
- 20-50% ● Chikwawa: 46.2% | Lilongwe: 38.1%  
Blantyre: 20.9% | Thyolo: 20.2%
- 10-20% ● Ntcheu: 19.4% | Dedza: 19.2%  
Mchinji: 14.8% | Balaka: 13.8%  
Zomba: 13.1% | Ntchisi: 12.5%
- 5-10% ● Chiradzulu: 9.7% | Mulanje: 8.3%  
Mangochi: 7.1% | Machinga: 5.0%
- Under 5% ● Phalombe: 4.3% | Nkhokotakota: 3.3%  
Salima: 0.0% | Dowa: 0.0%
- N/A ● New regions in 2025
- 0 ● Currently not served

## 4.3 Retention

Indicator	Tanzania	Malawi	Total
Patients registered end of 2023	7,345	2,562	9,907
Patients registered end of 2024	8,548	3,050	11,598
Patients seen in 2024	6,203	2,372	8,575
New patients seen in 2024	1,203	488	1,691
Existing patients seen in 2024	4,932	1,884	6,875
Patients who did not return in 2024	2,345	687	3,032
Annual retention rate	67.1%	73.5%	69.4%

Across both countries we saw 8,575 individual clients during 2024. This included 6,168 individual patients in Tanzania throughout 2024. Of these, 4,932 clients were returning within 12 months (representing an annual retention rate of 67.1%). In Malawi the picture was similar: in 2024 we saw 2,372 individual patients, of whom 1,875 were returning within 12 months (an annual retention rate of 73.3%). Across both countries in 2024 we saw 8,575 individual patients, of whom 6,875 were returning within 12 months (a combined annual retention rate of 69.4%).

Patient retention is a measure of the impact and effectiveness of the Skin Cancer Prevention Programme (SCPP). It reflects its ability to engage people with albinism in ongoing care and ensure consistent access to the services they need to prevent skin cancer.

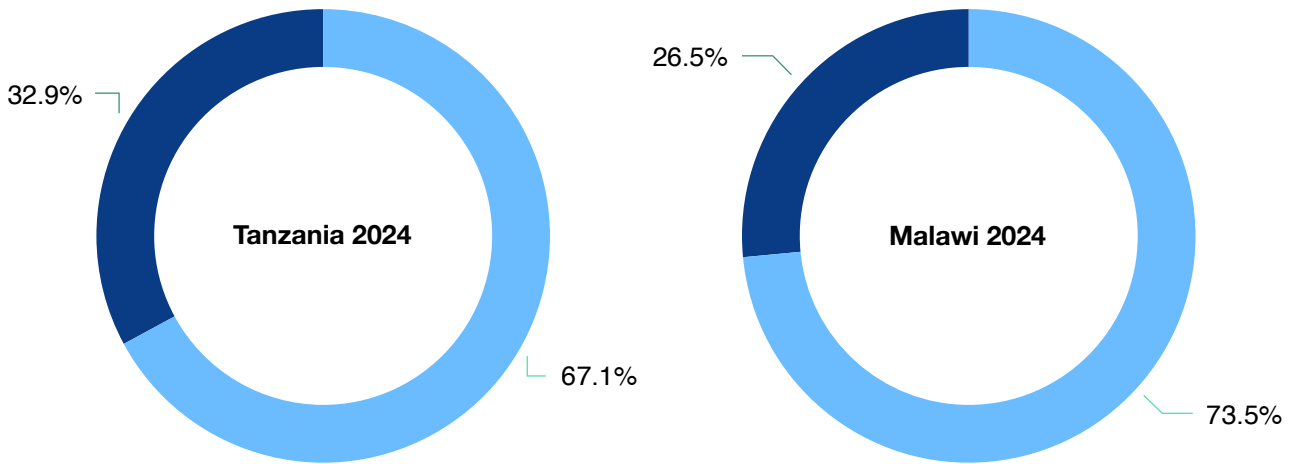
Maintaining high levels of retention is a complex, shaped by a range of external and personal factors. Barriers to attendance can include

- Work commitments, particularly for low-income individuals working in seasonal agriculture
- Environmental challenges, such as monsoons, flooding, road damage made worse by climate change
- Fear or anxiety around medical consultations or procedures
- Financial constraints, including transport to clinics
- Childcare responsibilities, which can make it difficult for caregivers to attend hospital
- Mistrust of health services, especially public health campaigns (e.g., vaccinations during Covid-19)
- Ongoing treatment, meaning patients may not prioritise attending Dermatology services
- Lack of awareness, where people simply haven't heard about upcoming clinics

Recognising these obstacles is vital to improving services, tailoring support, and developing responsive systems that encourage consistent patient participation. Sustaining retention means listening to the needs of our communities and adapting our approach to ensure the best possible access is available where they live.



● Patients returning within 12 months ● Patients not returning within 12 months



While achieving universal retention is challenging, we work hard at maximising accessibility and improving patient retention by identifying and addressing barriers to attendance wherever possible. Our electronic database enables us to closely monitor retention trends and conduct in-depth analysis. In 2024, we focused on understanding variations in retention across different locations, age groups, and genders, helping us pinpoint populations most at risk of dropping out. This insight allows us to direct additional resources towards mobilisation efforts targeted at these vulnerable groups.

We also use CommCare to ask structured questions aimed at identifying the specific facilitators and barriers that influence patients' ability to attend SCPP clinics. These insights are instrumental in refining our strategies.

Throughout 2024, we continued to scale up our use of direct SMS communications to inform patients about upcoming clinic dates. This approach has strengthened and diversified our mobilisation efforts, making patient outreach more timely and personalised. SMS also enables us to track and follow up with patients who deviate from regular attendance patterns or are identified as high risk. For example, we can flag individuals who haven't returned to a clinic in over 12 months and contact them directly to explore reasons for disengagement and encourage re-engagement.



## Mobilisation Strategies and Evaluation

To ensure strong patient turnout at clinics, we implement a diverse and targeted range of mobilisation strategies designed to reach people with albinism (PWA) and their families. These efforts are coordinated in close partnership with local Albinism Associations Leaders, Government Social Welfare Departments, and schools, who play a vital role in community outreach. In addition to these grassroots efforts, we utilise mass communication channels, including radio broadcasts, social media platforms, and direct SMS messaging to broaden our reach and ensure timely awareness of upcoming clinics. To assess the effectiveness of these mobilisation efforts, clients are asked a series of questions during clinic registration about how they heard about the service. The table below presents an analysis of the most effective mobilisation channels used during 2024.

How did you hear about the clinic?	Tanzania 2024		Malawi 2024		Total	
<b>Number of people surveyed</b>	9,862		3,847		13,709	
<b>MSN message</b>	2,308	23.4%	186	4.8%	2,494	18.2%
<b>Albinism Associations</b>	5,347	54.2%	2,433	63.2%	7,780	56.8%
<b>Social Welfare Officers / Health Surveillance Assistants</b>	1,204	12.2%	782	20.3%	1,986	14.5%
<b>Teacher / School</b>	689	7.0%	269	7.0%	958	7.0%
<b>Relative / Neighbour</b>	52	0.5%	31	0.8%	83	0.6%
<b>Radio advert</b>	14	0.1%	39	1.0%	53	0.4%
<b>Social Media</b>	167	1.7%	69	1.8%	236	1.7%
<b>Other</b>	81	0.8%	38	1.0%	119	0.9%

From the table above, we observe a similar pattern of success across the different mobilisation methods deployed in both countries. The most common way people with albinism reported hearing about clinics was through their albinism association leaders, accounting for 54.2% of all persons with albinism (PWA) mobilised in Tanzania and 63.2% in Malawi. Social Welfare Officers and Health Surveillance Assistants also played a significant role in patient mobilisation, with 12.2% of patients in Tanzania and 20.3% in Malawi hearing about clinics through these government actors. The education system continued to be a key channel for reaching PWA in both countries, with 7.0% of patients in Tanzania and 7.0% in Malawi reporting that they were referred by teachers or schools. In 2022, Standing Voice introduced direct MSN messaging to patients' phones in Tanzania. Its impact has continued to grow into 2024, with 23.4% of PWA in Tanzania and 4.8% in Malawi citing this method as how they learned about clinic services. The lower figure in Malawi is attributed to both reduced access to mobile phones and the later rollout of MSN messaging, which began there in 2023.

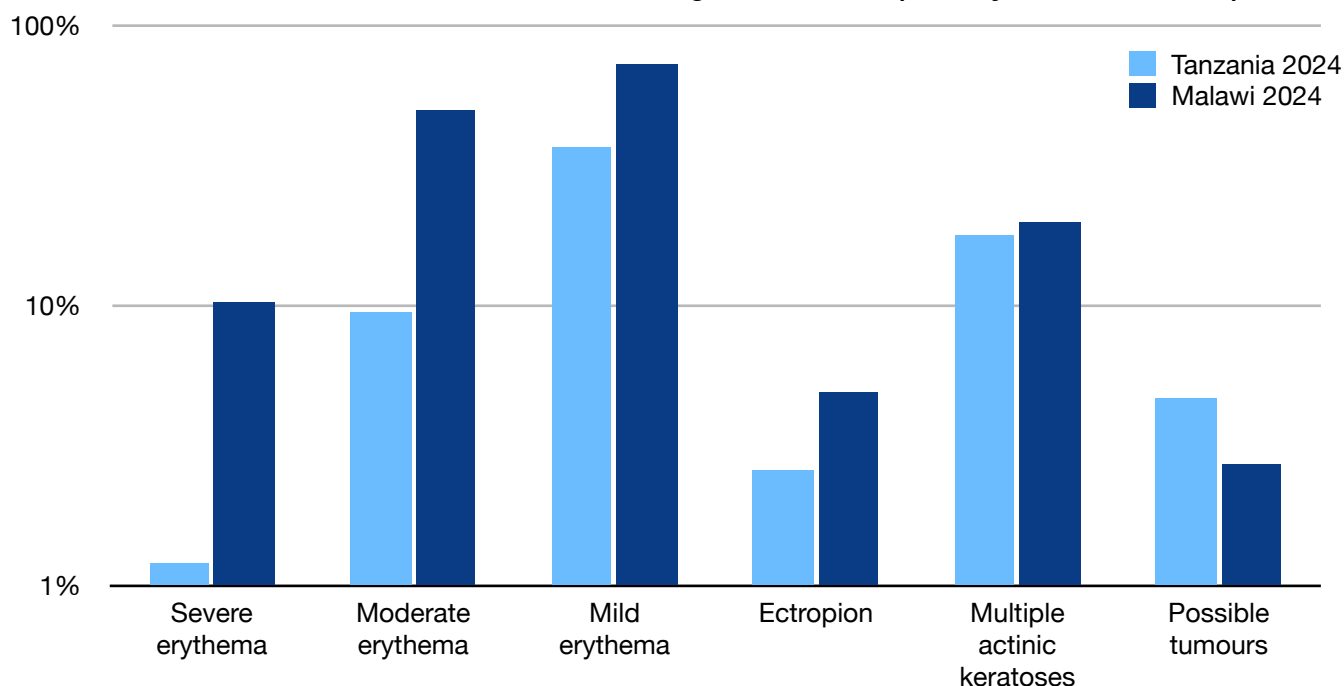


## 4.4 Screening and Medical Management

2024 Indicator	Tanzania		Malawi		Total	
<b>Total patients seen</b>	6,126		2,372		8,498	
<b>Number of examinations</b>	9,852		3,847		13,709	
<b>Number of cryotherapy procedures<sup>7</sup></b>	3,356	34.0%	2,133	55.4%	5,489	N/A
<b>Number of patients receiving cryotherapy</b>	1,468	24.0%	871	36.7%	2,339	27.5%
<b>Number patients referred for surgical procedures</b>	335	5.5%	85	3.6%	420	4.9%
<b>Number of examinations where patients present with...</b>						
Severe erythema	70	0.7%	392	10.2%	462	5.4%
Moderate erythema	915	9.3%	1,926	50.0%	2,841	33.4%
Mild erythema	3,642	37.0%	2,799	72.8%	6,441	75.8%
Ectropion	164	2.6%	189	4.9%	353	4.2%
Multiple AKs	1,076	17.6%	763	19.8%	1,839	21.6%
Possible tumours	289	4.7%	80	2.7%	369	4.3%

Clinical data from this reporting period indicates a higher prevalence of skin conditions among patients in Malawi compared to Tanzania. When measured as a proportion of the total number of clinical examinations, Malawi recorded significantly greater use of cryotherapy, with 55.4% of patients receiving the treatment, compared to 34.0% in Tanzania. Actinic keratoses were identified in 19.8% of all examinations in Malawi, slightly higher than the 17.6% recorded in Tanzania. Additionally, rates of erythema (sunburn) were consistently and significantly higher in Malawi—between three and ten times more prevalent across all three severity indicators: mild, moderate, and severe. This disparity is consistent with expectations, given the longer operational history of the SCPP in Tanzania, which has helped establish a stronger baseline of awareness and understanding around skin cancer prevention and protective behaviours among people with albinism. It is also important to note that this data includes new patients, many of whom had never accessed dermatological services before. This influx of first-time clients likely contributes to the higher rates of skin conditions observed, particularly in Malawi.

**Prevalence of Clinical Conditions among Patients Seen (January – December 2024)**

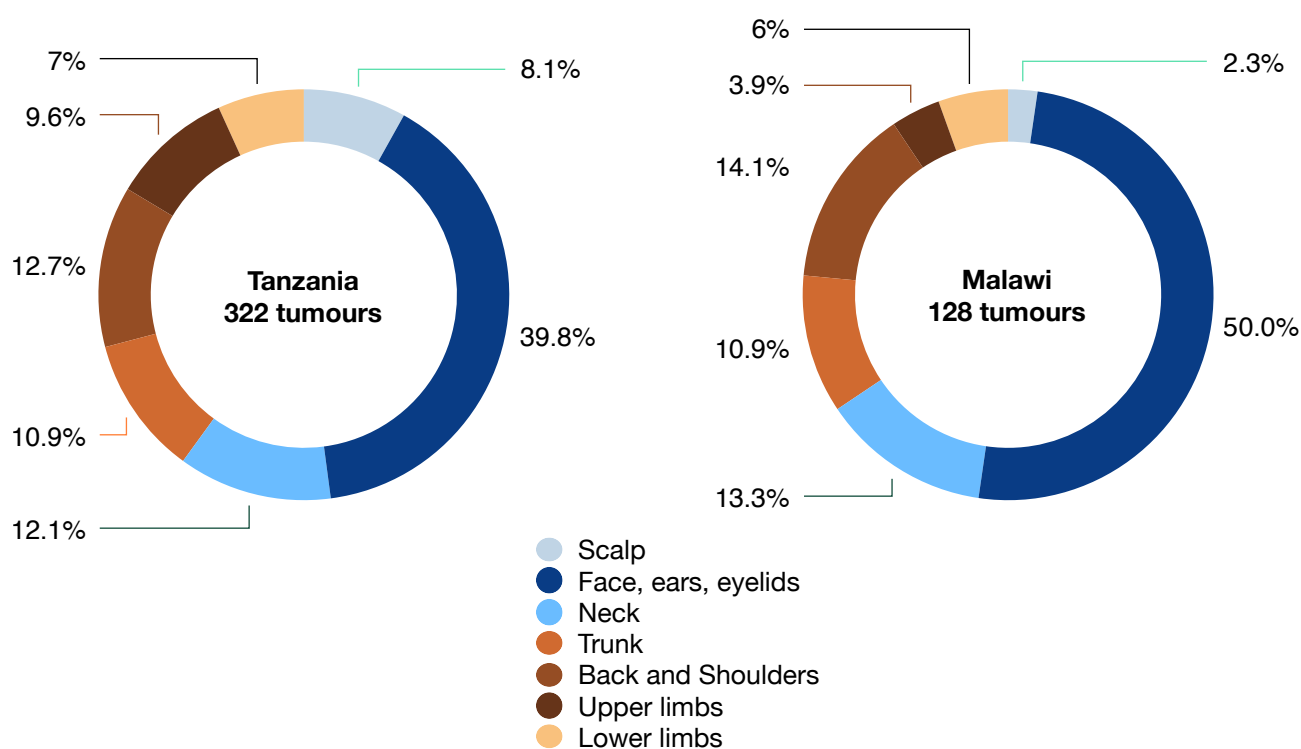


Provisional doctor's diagnosis during clinics 2024				
Indicator	Tanzania		Malawi	
<b>Possible tumours identified during clinics</b>	<b>322</b>		<b>128</b>	
<b>SCC</b>	111	34.5%	71	55.5%
<b>BCC</b>	176	54.6%	41	32.0%
<b>Ophthalmology or other condition</b>	35	10.9%	16	12.5%
<b>Distribution of possible tumours by body part</b>	<b>322</b>		<b>128</b>	
<b>Scalp</b>	26	8.1%	3	2.3%
<b>Face, ears, eyelids</b>	128	39.8%	64	50%
<b>Neck</b>	39	12.1%	17	13.3%
<b>Trunk</b>	35	10.9%	14	10.9%
<b>Back and shoulders</b>	41	12.7%	18	14.1%
<b>Upper limbs</b>	31	9.6%	5	3.9%
<b>Lower limbs</b>	22	6.8%	7	5.5%

A total of 450 possible tumours were identified during SSCP clinics across Tanzania and Malawi in this reporting period. In Tanzania, clinicians identified 322 possible tumours in 335 patients (a reduction from 396 possible tumours identified in 2023). Of these, 34.5% of possible tumours were identified as squamous cell carcinomas (SCCs), down from 44.4% in 2023. Basal cell carcinomas (BCCs) accounted for 54.7% of cases, up from 45.7% in the previous year. The remaining 10.9% were classified as other conditions, slightly up from 9.8% in 2023. In Malawi, doctors identified 128 possible tumours in 85 patients, a significant decrease from 255 tumours identified in 2023. Of these, 55.5% were diagnosed as SCCs (down from 61.2%), 32.0% as BCCs (up from 20.4%), and 12.5% as other or unspecified conditions (down from 18.4%).

The distribution of tumours by body part was similar across both countries. The majority were located on sun-exposed areas, with the face, ears, eyelids, neck, and scalp accounting for 60.0% of all tumours in Tanzania and 66.3% in Malawi.

**Distribution of tumours by body parts in 2024**



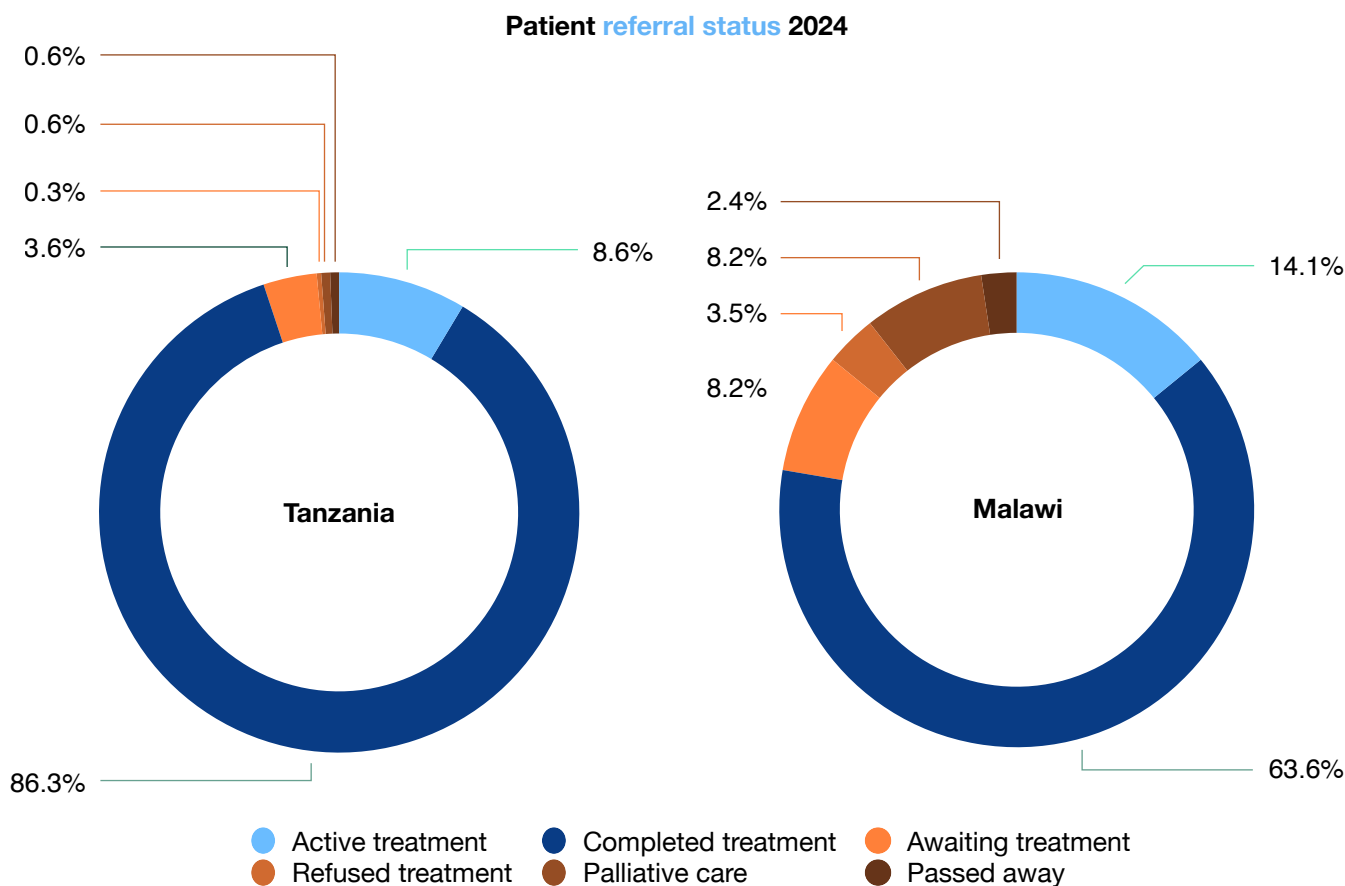
## 4.5 Referral Management

From January to December 2024, 422 patients were referred for skin cancer treatment by dermatologists at SCPP clinics. This included 335 people in Tanzania and 87 in Malawi.

Patient Referral Status 2024							
Indicator	Tanzania		Malawi		Total		
<b>Total number of patients sent for referral</b>	<b>335</b>		<b>85</b>		<b>420</b>		
<b>Completed treatment</b>	289	86.3%	54	63.6%	343	81.7%	
<b>Active treatment</b>	29	8.6%	12	14.1%	41	9.8%	
<b>Awaiting treatment</b>	12	3.6%	7	8.2%	19	4.5%	
<b>Refused treatment</b>	1	0.3%	3	3.5%	4	1.0%	
<b>Undergoing palliative care</b>	2	0.6%	7	8.2%	9	2.1%	
<b>Passed away</b>	2	0.6%	2	2.4%	4	1.0%	

This year there were 335 referrals made in Tanzania and 87 in Malawi. Encouragingly, at the end of December 2024 the majority of referred patients have either completed their treatment (86.3% in Tanzania and 63.6% in Malawi) or are undergoing active treatment (8.6% in Tanzania and 14.1% in Malawi), while 3.6% and 8.2% of patients respectively were awaiting treatment. In new locations the SCPP continues to see patients with advanced tumours. Of people referred in 2024, 2 patients in Tanzania and 7 patients in Malawi are undergoing palliative care support. 4 patients passed away from skin cancer during the reporting period (2 in Tanzania and 2 in Malawi).

A small minority of patients have refused treatment due to a number factors. Patients sometimes refuse treatment in fear of surgery, or because of financial or logistical obstacles involved in leaving their homes, jobs or families and travelling to receive treatment.



Referral Results 2024							
Indicator	Tanzania		Malawi		Total		
Patients for whom histology results are available	311		74		385		
<b>Confirmed diagnoses<sup>5</sup></b>	<b>320</b>		<b>106</b>		<b>426</b>		
<b>SCC</b>	138	43.1%	15	14.2%	153	35.9%	
<b>BCC</b>	105	32.8%	63	59.4%	168	39.4%	
<b>Melanoma</b>	1	0.3%	0	0.0%	1	0.2%	
<b>Ectropion and other Ophthalmological condition</b>	21	6.6%	2	1.9%	23	5.4%	
<b>Other e.g. ulcers, benign lesions, warts, cysts etc.</b>	55	17.2%	26	24.5%	81	19.0%	

In 2024, we received histology results for a total of 426 biopsies. 320 of these were from Tanzania and 106 from Malawi. In Tanzania, 43.1% of cases were confirmed as squamous cell carcinomas (SCCs), reflecting a reduction from 49.4% in 2023. Basal cell carcinomas (BCCs) accounted for 32.8% of results, also a decrease from 44% the previous year. Meanwhile, 17.2% were classified as other benign or non-cancerous conditions, marking a notable increase from 6.6% in 2023. Additionally, 6.6% of cases were referred for ophthalmological assessment. In Malawi, 14.2% of biopsy results were confirmed as SCCs, a significant decrease from 38.3% in 2023. BCCs comprised 59.4% of results, up from 51.0% the previous year, while 24.5% were identified as other conditions, an increase from 10.7% in 2023. A total of 23 individuals in Malawi were referred to ophthalmology services.

5. Patients often present with multiple lesions and as a result will have multiple biopsies taken. This is why the number of confirmed diagnoses is greater than the number patients with histology results available

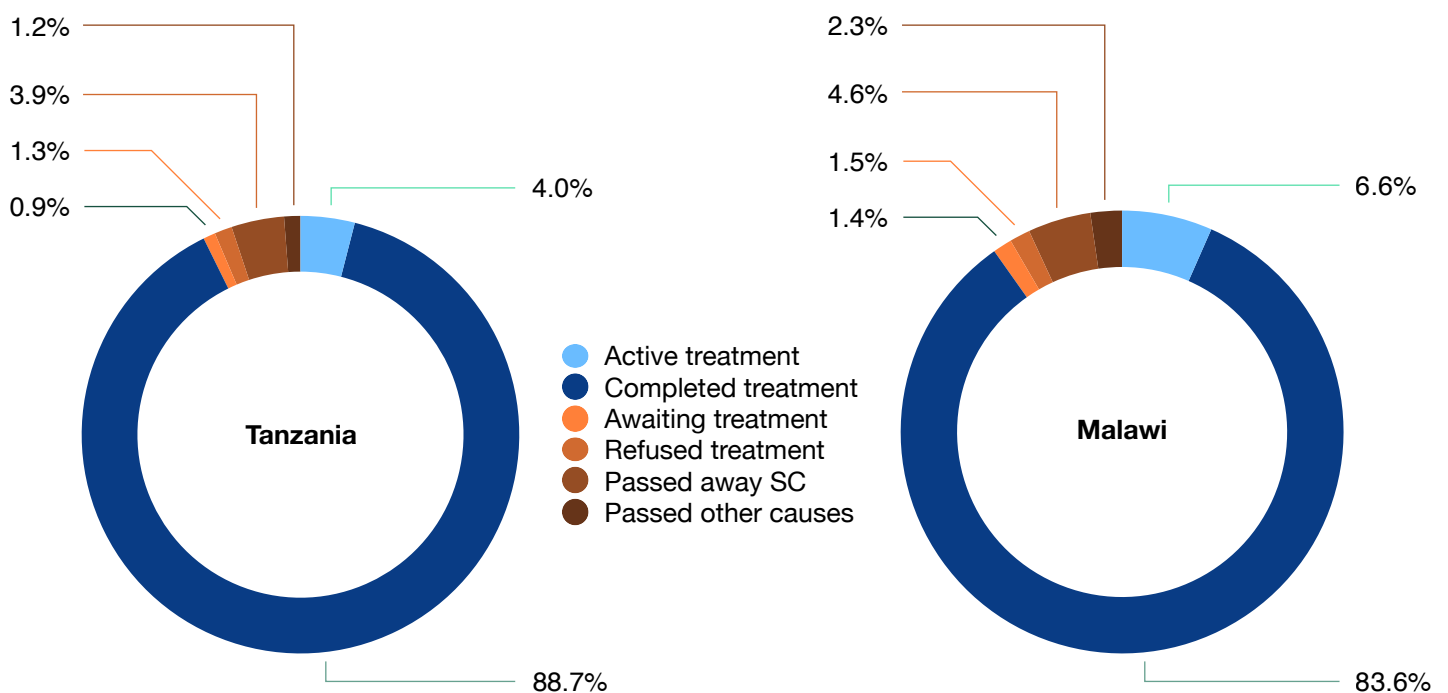
*“I’ve had operations for skin cancer several times. I would not be alive today without access to clinics. In my village, no one knew what albinism was, and, I myself, knew little about what causes albinism.”*  
*Barnabas Magashi Shilinde, Biharamulo, Kagera district, Tanzania*



Total patient referrals and status since 2017						
Indicator	Tanzania		Malawi		Total	
<b>Total number of patients referred for surgery</b>	<b>1,340</b>		<b>517</b>		<b>1,857</b>	
<b>Completed treatment</b>	1,189	88.7%	432	83.6%	1,621	87.3%
<b>Active treatment</b>	53	4.0%	34	6.6%	87	4.7
<b>Waiting for treatment</b>	12	0.9%	7	1.4%	19	1.0%
<b>Refused treatment</b>	18	1.3%	8	1.5%	26	1.4%
<b>Passed away from skin cancer</b>	52	3.9%	24	4.6%	76	4.1%
<b>Passed away from other causes</b>	16	1.2%	12	2.3%	28	1.5%

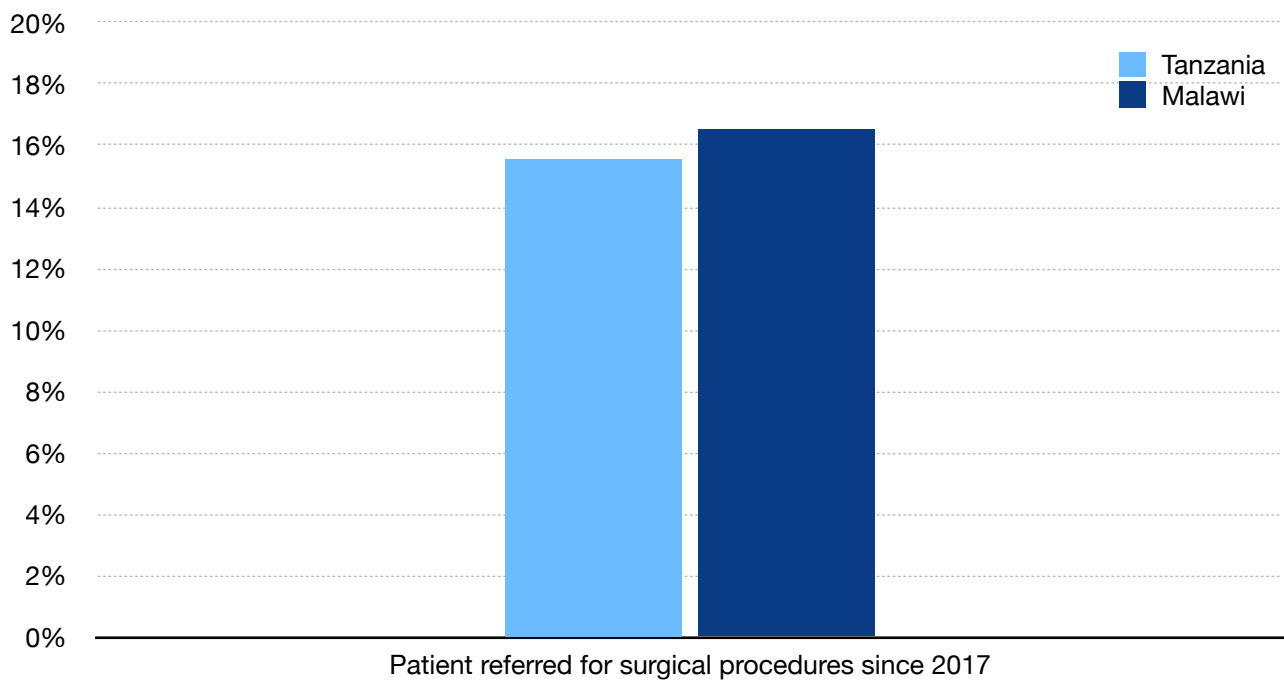
Across Tanzania and Malawi there has been a total of 1,857 referrals made through the SCPP since 2017. 1,340 of these have been made in Tanzania and 517 in Malawi. The vast majority of patients referred for skin cancer treatment since 2017 have completed their treatment (88.7% in Tanzania and 83.6% in Malawi). Some patients continue to undergo active skin cancer treatment (4.0% in Tanzania and 6.6% in Malawi), which includes 7 patients in Tanzania and 22 patients in Malawi who are currently receiving palliative care treatment. 76 patients registered in the SCPP have passed from from skin cancer since 2017 (52 in Tanzania and 24 in Malawi). 28 people have been documented to have passed away from other causes (16 in Tanzania and 12 in Malawi).

**Patient referral status 2017-2024**



*"Thanks to Standing Voice, I was able to have a wound [skin cancer] on my face removed. After this experience I now always return to [clinics] get my skin checked, and the [clinical] team have become like a family to me. At clinics, patients are treated well and we are able to learn more about our condition [albinism] and receive healthcare. I can now get free sunscreen and sun hats when I need it to protect my skin".*  
**Rose Temaheri Joseph, Tabora, Tanzania**

## Percentage of all registered patients referred for skin cancer surgery since 2017



15.6% (increase from 13.6% in 2023) of all registered patients in Tanzania and 16.5% (reduction from 19.8% in 2023) of all registered patients in Malawi have been referred for surgery or other treatments since 2017. These are high percentages that demonstrate the scale of the skin cancer crises facing people with albinism in Africa.



## 4.6 Sun Protection Measures

Indicator	Tanzania				Malawi				Total all years
	S2 2021	2022	2023	2024	S2 2021	2022	2023	2024	
<b>Number of jars of sunscreen distributed</b>	8,894	14,816	22,093	30,108	1,722	12,300	13,839	16,592	120,364
<b>Number of individuals receiving sunscreen</b>	3,269	4,651	5,247	6,203	661	1,521	1,978	2,372	25,902
<b>Number of sunglasses distributed</b>	0	3,795	5,214	2,570	15	269	177	198	12,238
<b>Number of hats produced locally</b>	4,381	7,458	13,350	17,676	N/A	N/A	N/A	N/A	42,865
<b>Number of hats distributed</b>	3,269	7,290	8,345	9,685	238	1,431	2,620	3,235	36,113
<b>Number of umbrellas distributed</b>	192	505	692	987	0	29	20	2	2,427
<b>UV protective lip balm</b>	0	0	0	0	0	567	876	503	1,946

In 2024, the SCPP distributed thousands of essential sun-protective items across Tanzania and Malawi, including over 46,700 bottles of sunscreen, over 12,000 wide-brimmed hats, close to 1,000 umbrellas, and just under 2,800 pairs of sunglasses.

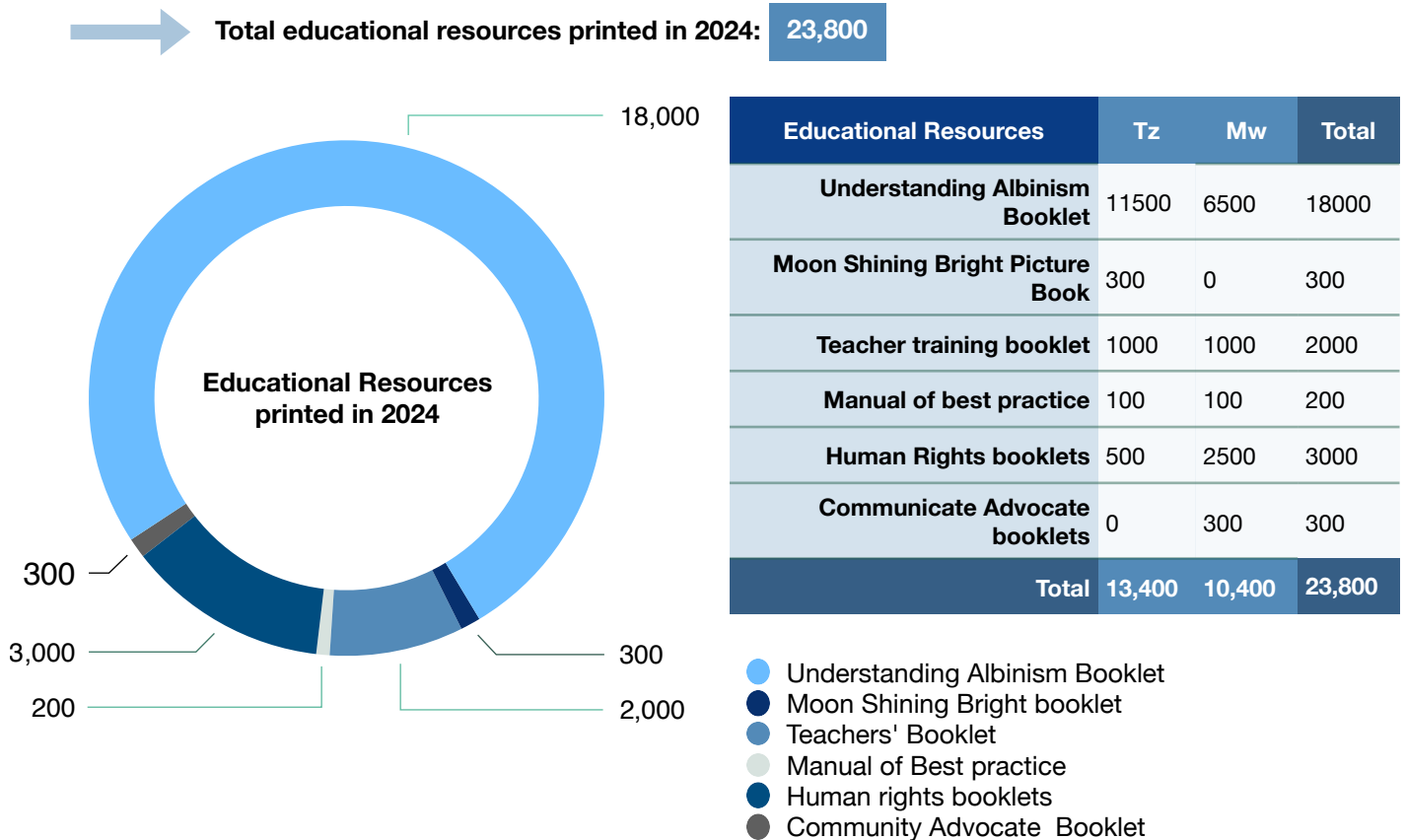
Since the launch of the Phase II initiative of the SCPP in July 2021, a total of 173,088 sun-protective items have been distributed to people with albinism across both countries. Among these, 42,865 wide-brimmed hats have been made locally by tailors with albinism at the Standing Voice Umoja Training Centre in Tanzania and distributed free of charge through the SCPP clinical network. In 2024, we continued to expand the production and export of these hats to Malawi, deepening our regional impact while further empowering people with albinism through inclusive, skills-based employment.



## 4.7 Educational resources

The SCPP serves as a key platform for disseminating specialist educational resources. Standing Voice has developed a diverse range of resources including booklets, training manuals and films to educate patients, communities, and service providers. In 2024, we printed and distributed 23,800 educational materials across all programme areas. Of these, 13,400 were distributed in Tanzania, 10,400 in Malawi.

To strengthen healthcare capacity, we continued to distribute and apply the *Manual of Best Practice in Dermatological Care for Persons with Albinism* to support professional training and enhance service delivery.



In 2024, educational resources were distributed through clinics, counselling, training sessions, and directly in schools across Tanzania and Malawi. These included multilingual booklets for people with albinism, families, teachers, and advocates; the illustrated children's story Moon, Shining Bright!; and the Manual of Best Practice for managing skin cancer in persons with albinism.

Educational films were screened throughout 2023 at advocacy events and clinic waiting areas, including an animated adaptation of Moon, Shining Bright! and Jikubali, a documentary co-produced with local partners. A new EU-commissioned documentary was also launched, highlighting our programmes in Malawi.

By equipping communities with accessible, engaging resources, we are helping thousands of people with albinism, and those around them, to better understand their rights, protect their health, and challenge stigma. From frontline health services to classrooms and community gatherings, these tools are fostering awareness, promoting inclusion, and driving lasting behavioural change across Tanzania and Malawi.



*"I have been attending clinics for the past 8 years. When I compare my health today to how it used to be, it's easy to see how my life has changed. These clinics have saved my life.  
Siyajali Magenge, Kigoma, Tanzania*

## 4.8 Community Knowledge

	Indicator	Tanzania	Malawi	Total
	Number of awareness sessions	400	238	638
	Number of patients and their relatives present at awareness sessions	12,112	5,149	17,261
	Number of communication tool(s) used for the general public	4	5	9
	Number of communication tool(s) distributed in the form of a brochure	12,329	7,418	19,747
	Number of community advocate training events	7	7	14
	Number of 'community advocates' trained	85	176	261

Over the past 12 months, the SCPP delivered 638 health awareness sessions across Tanzania and Malawi, reaching a total of 17,261 people, including people with albinism, their family members, teachers, and community representatives. In Tanzania, 400 sessions were delivered to 12,112 participants, averaging 1.6 sessions per clinic. In Malawi, 238 sessions reached 5,149 people, with an average of 1.7 sessions per clinic. Additionally, 19,747 educational booklets were distributed to people with albinism in both countries.

In 2024, we conducted seven Community Advocate Training events in two new regions of operations in Tanzania (Mtwara and Iringa), and seven more across six districts in Malawi (Ntcheu, Mchinga, Mulanje, Zomba, Neno, and Mwanza). These workshops engaged Community Leaders, Health Surveillance Assistants, Social Welfare Officers, and District Committee members of Albinism Associations, equipping them to better advocate for and protect the rights and welfare of people with albinism in their communities.



## 4.9 Stakeholder Training

In addition to delivering direct health education to people with albinism and their families, the SCPP drives systemic change in Tanzania and Malawi by strengthening the capacity of key duty bearers. These individuals, such as health professionals, educators, and government stakeholders, play a vital role in improving the health, wellbeing, and inclusion of people with albinism, particularly in the prevention and treatment of skin cancer.

In 2024, prior to launching new SCPP clinical services in new locations of each country we conducted 21 stakeholder engagement workshops, 17 of these were in Tanzania and 4 in Malawi. These workshops introduced the programme to key stakeholders, mapped local hospitals, health centres, and patient populations, and identified optimal clinic locations. Sessions also covered understanding albinism, delivering effective health education, clinic setup, data collection, and referral management. Participants included Regional Administrative Secretaries, District Medical Officers, Social Welfare Officers, Special Education Officers, facility heads, and district and regional representatives of the Tanzania Albinism Society (TAS) and the Association of Persons with Albinism in Malawi (APAM). In total, these workshops trained 254 stakeholders, 133 in Tanzania and 121 in Malawi.

During the same period, clinical training was delivered to 103 frontline health professionals, 55 individuals in Tanzania and 48 in Malawi, including Dermatology Officers, Surgical Officers, Medical Assistants, nurses, and Health Surveillance Assistants. Training consisted of one to two days of classroom-based instruction followed by three to five days of hands-on clinical or theatre-based practice for dermatology and surgical staff.

Across all training initiatives in 2024, the SCPP strengthened the capacity of 618 key duty bearers: 273 in Tanzania and 345 in Malawi.



Photo: Community Advocate Training Event in Ntcheu District, Malawi in Jan 2024

#### 4.9.i IN FOCUS: 2024 Clinical and Surgical Training

In August 2024, Standing Voice conducted a week-long clinical training workshop in Mwanza, targeting Dermatology and Surgical Officers from across the country. The training specifically focused on enhancing skills in the prevention, early detection, and management of skin cancers in persons with albinism, and was led by experts from the Regional Dermatology Training Centre in Moshi Dr Mavura, alongside a team of Consultant Dermatologists from Leicester Royal Infirmary: Dr Sharp, Dr Roberts and Dr Twigg. Strengthening the clinical workforce across Tanzania in this way is a key element of the SSCP's efforts to decentralise services and improve early intervention outcomes closer to clients' homes.

During 2024, Standing Voice delivered nine specialised workshops targeting health professionals, including seven focused on skin cancer prevention and management for people with albinism (PWA) and two dedicated to surgical skill development. Trainings were guided by our *Manual of Best Practice for Skin Cancer Prevention and Management in PWA*, developed in partnership with the International Foundation of Dermatology, International League of Dermatological Societies, and Pierre Fabre Foundation.

Training sessions combined interactive lectures, practical exercises, and digital data training, tailored to participant roles. Day 1 covered core dermatology and albinism care concepts, including sun exposure effects, skin cancer detection, patient education, and referral pathways. Day 2 focused on surgical skills for Dermatology Officers, covering anatomy, anaesthesia, biopsy, suturing, and post-operative care.

All trainings included pre-and-post-assessments, demonstrating improvements in knowledge, confidence, and clinical competence. Trainees also benefited from mentored clinical practice, applying skills under expert supervision to promote real-world experience and sustainability. In addition in-clinic capacity strengthening and mentorship for health workers has been an ongoing focus throughout the course of the past 12 months.



*Dr Emily Twigg provides guidance and mentorship to trainee clinicians during a Surgical training day in theatre in Mwanza Tanzania, August 2024*



The table below shows the large number of actors working across the programme. Today there are 2,217 people involved in delivering the SCPP.

By the end of 2027 we aim to have trained and mobilised over 2,500 frontline workers to lead the delivery of this programme.

SCPP stakeholders	Tanzania	Malawi	Total
Dermatologists and Dermatology Officers	48	28	76
Albinism Association leaders	276	136	412
Social Welfare Officers & Health Surveillance Assistants	171	96	267
Other health personnel: Clinicians, Medical Assistants, Nurses, Surgeons, Histopathologists	228	362	590
Regional & District Medical Officers	120	19	139
First responders / counsellors	24	30	54
Optometrists	20	12	32
Special Education Officers (Regional & District)	114	7	121
Teachers	451	-	451
Tailors	18	-	18
Pharmacists	8	17	25
Media	-	33	32
<b>Total</b>	<b>14,78</b>	<b>739</b>	<b>2,217</b>

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## 5. VISION AND EDUCATION PROGRAMME

People with albinism experience visual impairment due to a deficiency in melanin, which plays a critical role in the development of normal vision. Without proper intervention, this impairment can significantly hinder educational achievement and limit employment opportunities, particularly across Africa. Many individuals with albinism are pushed into subsistence farming, outdoor work that further exposes them to the heightened risk of skin cancer.

In countries like Tanzania and Malawi, access to specialist optometry services remains limited, both in terms of availability and affordability. Systemic discrimination further compounds these challenges, leaving most people with albinism without the vision care or educational support they need. Teachers often lack the training to accommodate students with visual impairments, placing these students at a further disadvantage in school.

Since 2014, Standing Voice has been implementing a comprehensive clinical programme focused on vision care, education, and training to address these barriers. Targeting primarily students, the programme supports a network of eye clinics offering specialist low vision assessments and assistive devices, including monocular telescopes, prescription glasses, sunglasses, and health education materials. It also works to build the capacity of optometrists and educators to better meet the needs of people with albinism.

The Vision and Education Programme (VEP) is delivered in collaboration with the Government of Tanzania and various civil society partners. As of December 31, 2024, the VEP had registered 5,161 individuals with albinism across 15 regions of Tanzania. In 2024, the programme was successfully launched in Malawi, enrolling and screening an additional 209 clients.



*“The Vision Programme has had a very positive impact on my life and I am confident that it will continue to help my fellow brothers and sisters with albinism in Tanzania for years to come.”*  
**Student - 17 years old- Dar Es Salaam**

## 5.1 Key Achievements in 2024

### ➔ Total people with albinism supported: 2,757

In 2024, the Vision Programme delivered seven large-scale eye clinics across Tanzania, reaching 2,757 people with albinism. Patients were mobilised from eight regions: Mwanza, Shinyanga, Dar es Salaam, Pwani, Geita, Tanga, Kagera, and Morogoro, ensuring broad geographic coverage and access. The programme also marked a significant milestone with the launch of the Vision and Education Programme (VEP) in Malawi, where the first large scale clinic was held in Lilongwe in July 2024.

All persons attending received individual consultations and comprehensive eye examinations, along with education on albinism and visual impairment. Each participant was also provided with tailored resources and assistive devices to support the daily management of low vision and improve quality of life.

### ➔ Total assistive vision devices distributed: 8,053

During the reporting period we distributed 8,053 assistive devices including 1,898 pairs of prescription glasses, 2,671, pairs of sunglasses, 1,575 monocular telescopes, 1,909 glasses cases.

### ➔ Teachers trained: 63

Throughout 2024, the Standing Voice Team delivered specialist training on albinism and inclusive education for 63 teachers from 16 schools in Tanzania.

### ➔ Students reached through seminars and school outreach 21,728

In addition to our eye clinics, we organised awareness and understanding albinism seminars in both schools and community settings. These events featured interactive talks designed to engage students and promote positive narratives around albinism and personal achievement. Delivered alongside our core clinical programme, the seminars provided one-to-one support for 1,415 students with albinism, while reaching 21,728 of the wider student body across 37 schools. To enrich these sessions, we incorporated book readings and film screenings that further encouraged empathy, inclusion, and understanding. As part of this wider initiative schools and students from across Ukerewe Island were invited to visit the Umoja Training Centre, where they accessed our community library, stocked with a range of Swahili and English books.



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## 5.2 Impact on Education

### 5.2.i TEACHER TRAINING

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In addition to delivering direct clinical care, the Vision Programme works to drive systemic change in Tanzania by strengthening the capacity of teachers to understand and respond to the visual needs of students with albinism. This is critical to enabling the next generation to realise their educational and professional potential and break the cycle of stigma and exclusion.

Since its inception in 2014, the programme has trained 451 teachers, now serving as Vision Ambassadors. These educators champion the rights of students with albinism, fostering a culture of inclusion, accountability, and respect within their schools. They also play a vital role in supporting clinical follow-up—monitoring students' vision needs, ensuring the appropriate use of assistive devices, and serving as key contacts for Standing Voice. This integrated approach is reinforced by optometrists who accompany the Standing Voice team to schools, providing on-site support and follow-up care for high-risk students.

During the reporting period, 63 teachers across 16 schools received in-depth training on albinism and inclusive education. An additional 21 schools were engaged through student-focused awareness activities. Across all 37 schools, Standing Voice staff worked to deepen understanding of albinism and promote inclusive learning environments.

In partnership with Vision Ambassadors and school leadership, tailored Action Plans were developed to improve the educational participation and wellbeing of students with albinism. Measures implemented included:

- Producing large-font examination papers
- Repainting blackboards and improving classroom lighting
- Reorganising seating to enhance visibility
- Providing after-class academic support
- Hosting school-wide assemblies to raise awareness about albinism
- Promoting sun protection, including sunscreen use and protective clothing
- Encouraging peer support, such as reading aloud for visually impaired classmates

Through these efforts, a total of 21,728 students were sensitised during the reporting period. Focus group discussions revealed notable improvements in the self-reported wellbeing and academic performance of students with albinism. Meanwhile, Likert-scale surveys showed increased teacher knowledge and confidence in supporting these students.

In addition, 17,261 people with albinism and their family members were reached with targeted health education at our Vision and Dermatology Clinics.

#### **Charles Maksio – Teacher - Mgugu Secondary School, Morogoro**

*“The [Vision] Programme plays a vital role in supporting the education of our students with albinism. As a teacher who regularly escorts them to eye clinics, I have witnessed firsthand the dedicated care provided by optometrists. The provision of specialised [visual] devices has had a big impact on their learning experience.*

*Before the programme began, many of these students struggled to keep up with their classmates. Now, with their visual aids, they are more attentive, actively participate in class discussions, and show a greater understanding of their studies. The [Vision] Programme has helped my students overcome a major barrier to education, allowing them to reach their full potential. It’s a privilege to witness the positive change this initiative brings to their lives”.*



### 5.3 Training of Optometrists

To improve access to eye care for people with albinism, Standing Voice partners with the Tanzania Optometric Association, the Kilimanjaro Christian Medical Centre (KCMC) School of Optometry, and a network of international experts to train optometrists in the diagnosis and treatment of low vision specific to this population. In 2024, 13 new optometrists received specialised training, this included 1 new person in Tanzania and 12 people in Malawi, bringing the total number of trained professionals supporting the Vision and Education Programme (VEP) to 32 across both countries.

As part of our ongoing expansion of the VEP into Malawi, we held two dedicated training workshops for optometrists. The first was an online seminar led by Dr Rebecca Kammer, a U.S.-based global expert in low vision and long-term strategic advisor to the programme. This was followed by an in-person workshop in Malawi, led by Tanzanian optometrist Abdi Nyembo, who also serves as a tutor at the KCMC School of Optometry. The trainings reviewed core clinical theory around the unique visual needs of people with albinism, including refractive strategies, prescribing and dispensing techniques, and approaches to specialised low vision screening. In the days that followed, trainees applied their new skills in a supervised clinical setting in Lilongwe, using our CommCare electronic patient management system and working directly with patients.

We are deeply grateful for the leadership of Dr Abdi Nyembo, who oversees the delivery of patient care and optometric training for Standing Voice, and to Dr Rebecca Kammer, a world-renowned authority on low vision in people with albinism, long term collaborator of Standing Voice and a key architect of the Vision Programme.

*“I’m so proud of the work we are doing at Standing Voice to train more optometrists as experts in low vision management. Together we are bringing transformational eye care to thousands of students with albinism and giving them the tools and knowledge they need to excel in life.”*

**Dr Abdi Nyembo, Head of Optometry and Training**

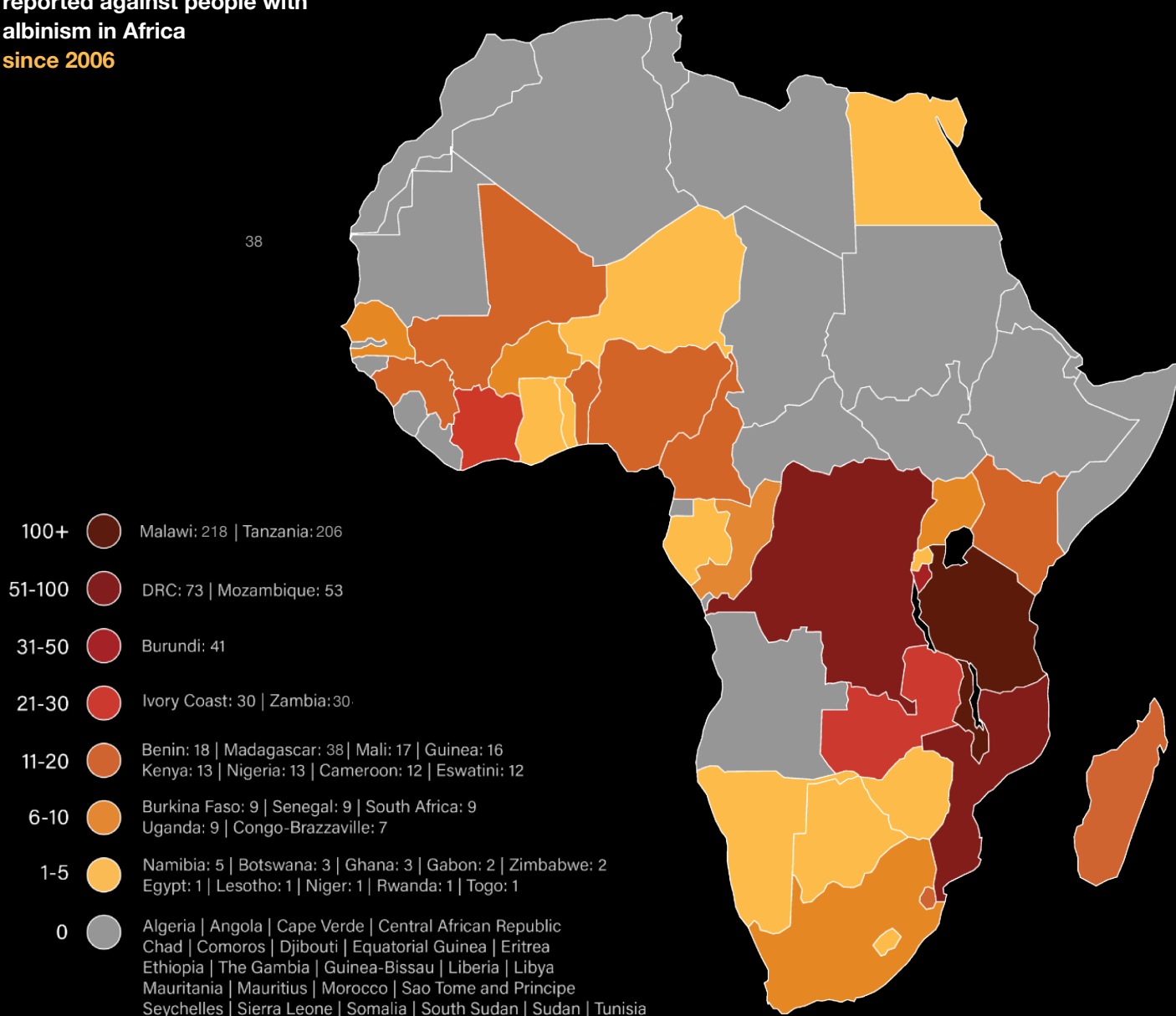


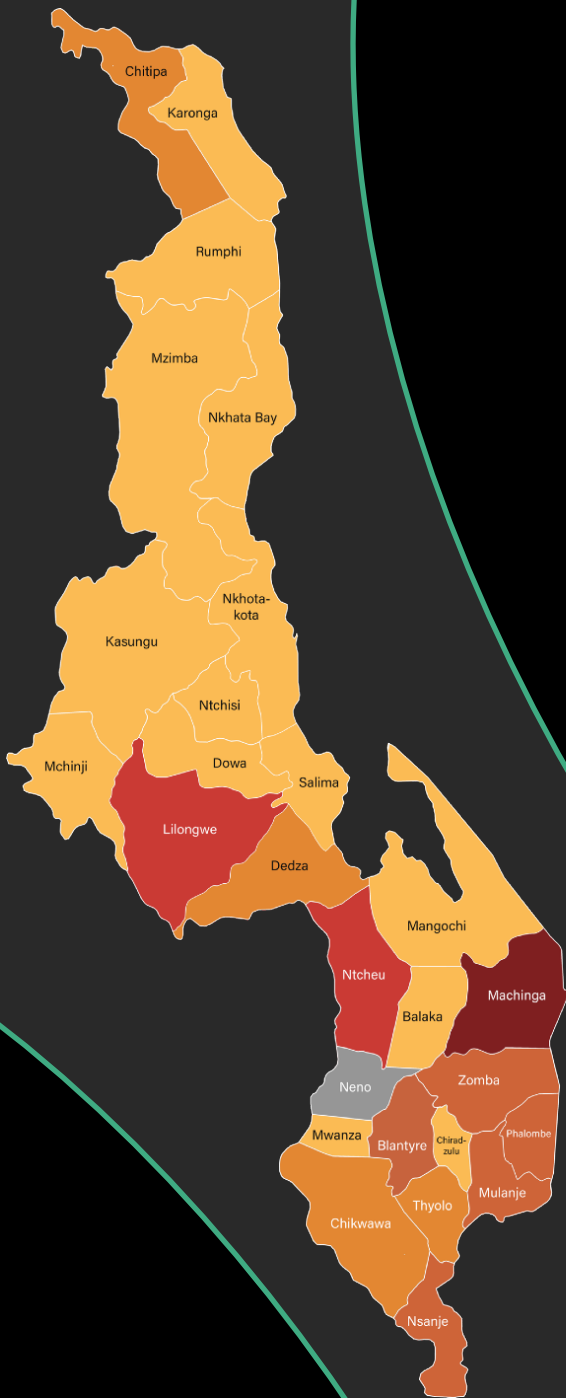
## 6. WELFARE AND SOCIAL PROTECTION PROGRAMME

### 6.1 The Issue

People with albinism are a violently persecuted minority in many African countries. Stigmatised for their unique appearance, many people with albinism are denied opportunities, excluded from services and subjected to damaging myths and misconceptions. In the worst cases, people with albinism are abducted, mutilated, raped and murdered: all because of the colour of their skin. As of December 2024 there were 831 reported human rights violations against persons with albinism in Africa. Tanzania and Malawi have been the continental epicentres of these atrocities; together, these two countries account for half of all human rights violations reported against people with albinism across the continent since 2006. In 2024 violent attacks against people with albinism in Malawi continued to escalate, with a string of attempted abductions and grave violations reported in southern and central districts of the country. 1 in 6 people with albinism living in Machinga District of Malawi have been victim to attack.

**853 human rights violations**  
reported against people with  
albinism in Africa  
since 2006





## MALAWI

### 218 human rights violations

reported against people with albinism since 2006

- 30+ ● Machinga: 38
- 16-30 ● Ntcheu: 17 | Lilongwe: 17
- 11-15 ● Zomba: 15 | Mulanje: 14 | Phalombe: 15 | Blantyre: 13 | Nsanje: 11
- 6-10 ● Dedza: 9 | Chitipa: 8 | Thyolo: 8 | Chikwawa: 7
- 1-5 ● Mangochi: 5 | Balaka: 4 | Salima: 4 | Chiradzulu: 4 | Karonga: 3  
Mchinji: 3 | Mwanza: 4 | Ntchisi: 5 | Dowa: 4 | Kasungu: 2  
Mzimba: 2 | Nkhata Bay: 2 | Nkhatakota: 2 | Rumphsi: 1
- 0 ● Neno

### Most recent attacks:

**18th July, 2024**

Attack on a 3-year old boy with albinism in Mwanza Region, Tanzania

**17th June 2024**

abduction and murder of a 2-year old girl with albinism in Kagera region, Tanzania

**4th May 2024**

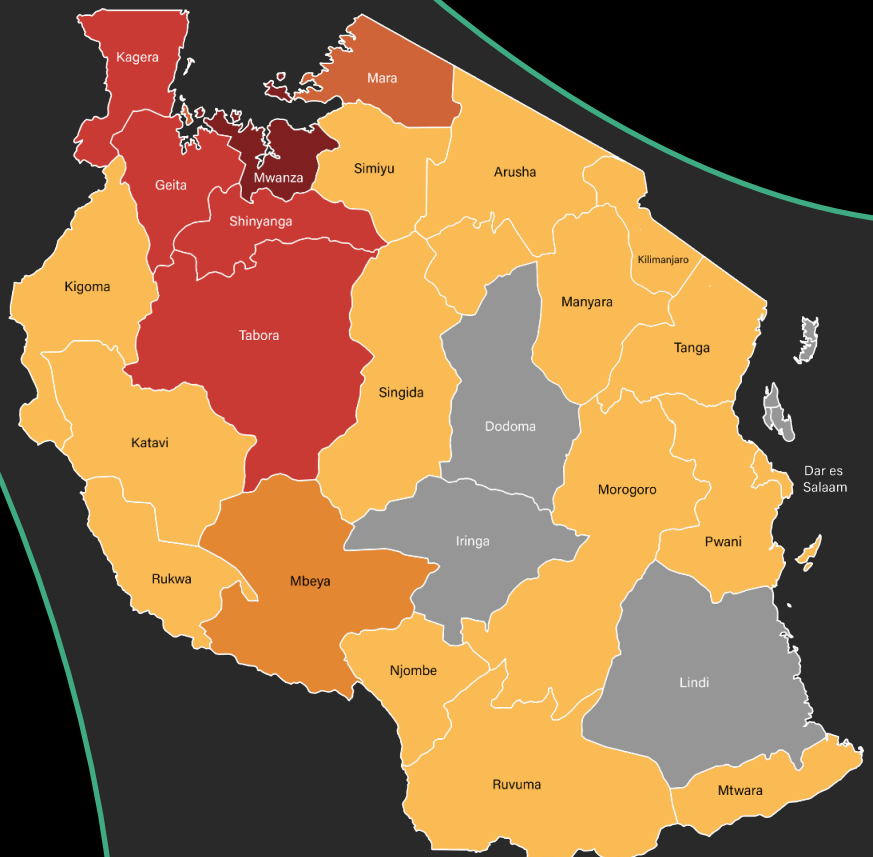
attack on a 10-year old boy with albinism in Geita Region, Tanzania

## TANZANIA

### 206 human rights violations

reported against people with albinism since 2006

- 30+ ● Mwanza: 55
- 16-29 ● Kagera: 25 | Geita: 17 | Shinyanga: 17 | Tabora: 16  
Unknown locations 16
- 11-15 ● Mara: 14
- 6-10 ● Mbeya: 6
- 1-5 ● Rukwa: 5 | Kigoma: 4 | Morogoro: 4 | Pwani: 4  
Arusha: 3 | Dar es Salaam: 3 | Simiyu: 3 | Tanga: 4  
Njombe: 2 | Katavi: 1 | Kilimanjaro: 1 | Manyara: 1  
Mtwara: 1 | Ruvuma: 1 | Singida: 1 | Songwe: 1
- 0 ● Dodoma | Iringa | Lindi | Zanzibar | Pemba



In addition to the persistent threats of violence and deeply rooted discrimination, most individuals with albinism whom we support in Tanzania and Malawi face significant barriers in accessing education, housing, financial stability, justice, and political inclusion. Many have experienced profound trauma and require tailored, specialist support to navigate these intersecting challenges.

Across both countries, the Standing Voice First Response Team plays a crucial role in identifying, addressing, and preventing instances of abuse and discrimination against people with albinism and their families. This dedicated team is made up of local Standing Voice staff, social welfare professionals, and individuals with lived experience of albinism-related stigma. Over the past four years, they have undergone training and continuous mentorship from Dr. Mark Fish, a UK based psychotherapist and a member of the Standing Voice Advisory Board.

The First Response Team serves as a critical support system for some of the most at-risk individuals in our network. In 2024, its core areas of intervention included:

## 6.2 Albinism Helpline

Indicator	Tanzania	Malawi
Regions where people with albinism have access to a helpline	21	19
Calls received through helpline	3,165	3,433

In 2024, Standing Voice continued to strengthen and operate two dedicated toll-free helplines, vital lifelines for people with albinism and their families across Tanzania and Malawi. These helplines offer confidential, accessible platforms to report abuse, raise urgent health or welfare concerns, and seek support in situations of risk or uncertainty. Calls are handled by a trained team skilled in conducting rapid needs assessments and determining the appropriate course of action. Depending on the nature of the call, support may include immediate over-the-phone guidance, referral to a Standing Voice programme including counselling, connection with specialist partner organisations, or, in cases of imminent danger, escalation to law enforcement or emergency services.

By the end of 2024, the helplines were accessible to people with albinism in 21 regions of Tanzania and 19 districts of Malawi, covering all areas where the Skin Cancer Prevention Programme (SCPP) is active. Awareness about these services continues to be raised through literature, outreach clinics, school-based activities, and broader community engagement.

Since their inception in 2021, the helplines have received 3,165 calls in Tanzania and 3,433 in Malawi. Callers seek support for a wide range of critical issues, most commonly:

- Reports of violence or abuse
- Anticipated or actual threats to personal safety
- Access to urgent medical care
- Psychosocial support
- Challenges related to education, food security, or livelihoods

Beyond their role in crisis response, these helplines are vital tools for ongoing case management and personalised care. They ensure that individuals at risk are not only heard but supported, reinforcing our commitment to leaving no one behind.

During the year, with support from the Evans Cornish Foundation, we established our first dedicated call centre in Mwanza, Tanzania. In parallel, with support from the child rights organisation C-Sema, we began developing a Customer Relationship Management (CRM) system to enhance the documentation, monitoring, and referral of incoming calls. The CRM is scheduled to launch in 2025.

## 6.3 Advocacy

Protecting the rights and dignity of people with albinism remained at the heart of our work in 2024. Through targeted advocacy, Standing Voice challenged harmful beliefs, promoted inclusion, and pushed for accountability from the ground up.

In Malawi, we confronted harmful myths and deep-rooted misconceptions through a wide-reaching programme of education and engagement. Under the EU-funded Ufulu Wanga project, we ran a four-week pop-up theatre tour across Ntcheu, Machinga, Zomba, and Mulanje, districts with some of the highest rates of attacks. These powerful performances opened space for dialogue, healing, and change. We also partnered with YONECO and Beyond Suncare to produce a ten-part radio series on albinism, broadcast nationwide and reaching millions of listeners with vital information on rights, protection, and inclusion.

In Tanzania, we continued our school- and community-based awareness initiatives, delivering Understanding Albinism seminars and assemblies. We hosted film screenings and supported the Tanzanian Albinism Collective in the production of a new music video, using the arts to elevate voices and shift perceptions.

Beyond our programme countries, Standing Voice remained a strong voice for international accountability and reform. As an organisation with special consultative status at the UN Economic and Social Council (ECOSOC), we contributed evidence and insight to UN mechanisms, including direct engagement with Muluka Miti-Drummond, UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, and Antoine Gliksohn, Executive Director of the Global Albinism Alliance. We also advanced the global visibility of albinism through film and media, including through screenings of our founding documentary *In the Shadow of the Sun*, acclaimed BBC documentary *Born Too White*, and through production of new short documentary commissioned by the EU, set for release in 2025.



# TANZANIA ADOPTS NATIONAL ACTION PLAN ON ALBINISM

## 6.3.i IN FOCUS: National Action Plan on Albinism

A major advocacy milestone was achieved in December 2024 with the ratification of Tanzania's National Action Plan (NAP) on Albinism. For the past five years Standing Voice proudly chaired the National Action Plan Committee, that spearheaded drafting and advocacy efforts that culminated in the plan's development and eventual adoption by the Government of Tanzania. We extend our sincere thanks to all members of the Committee, including the Prime Minister's Office and its technical team, the Tanzania Albinism Society, Under the Same Sun, and Beyond Inclusion, for their commitment to achieve this historic milestone for the albinism movement in Tanzania.

Building on this momentum, in January 2025, Standing Voice will host a roundtable in Mwanza with the Ministry of Health and national leadership of the Tanzania Albinism Society. The event will establish a dedicated task force to develop a new Quality Assurance Tool, an essential framework for evaluating the impact of the SCPP and strengthening government ownership. Through this initiative we aim to improve long term sustainability, and enhance the quality, reach, and consistency of health and welfare services for people with albinism across Tanzania.



## 6.4 Counselling and Emergency Tailored Support

Indicator	Tanzania	Malawi
Regions / districts where PWA have access to counselling at clinics	3	8
PWA with access to counselling service at clinics	1,924	1,484
People counselled through peer-to-peer counselling at clinics	140	198
Number of clinics with Counselling delivered	34	47
PWA receiving tailored and emergency support	150	101

During 2024 through the support of the Pierre Fabre Foundation, European Commission and United Nations Voluntary Fund for Victims of Torture we have been able to continue expanding peer to peer counselling and risk assessments at Dermatology clinics throughout Tanzania and Malawi, providing safe and confidential spaces for people with albinism and their families to speak freely about their needs and concerns, process trauma, build confidence and access referral for specialist services where required. By the end of 2024, counselling was accessible to 1,924 people with albinism across three regions of Tanzania and to 1,484 people in eight districts of Malawi. Across both countries a total of 338 individuals received counselling during the reporting period via delivery of 81 clinics. Of the 140 people visiting counselling stations during 2024 in Tanzania 94.3% were female and 5.7% Male. Of the 198 clients who received counselling in Malawi 49% were female and 51% Male.

For the most vulnerable people we work with, many of whom carry acute psychological trauma and have survived witchcraft-related atrocities, our Response Team provides a package of emergency support. This can include relocation to safe-housing, home security improvements; livelihood and food security support; urgent medical intervention; psychosocial, dermatological and palliative healthcare; facilitation of trauma recovery or family reconciliation; and direct advocacy interventions in situations of risk, conflict or exclusion. Across both countries 251 people with albinism received some form of tailored support during 2024. This included ongoing support to 22 survivors of attack and 21 of their family members.

- 1 in 6 PWA in Machinga Malawi have been victim to attack
- 76.67% of survivors we are working with are under 15 years old



## 6.5 Umoja Training Centre: Advancing Inclusion, Education and Opportunity

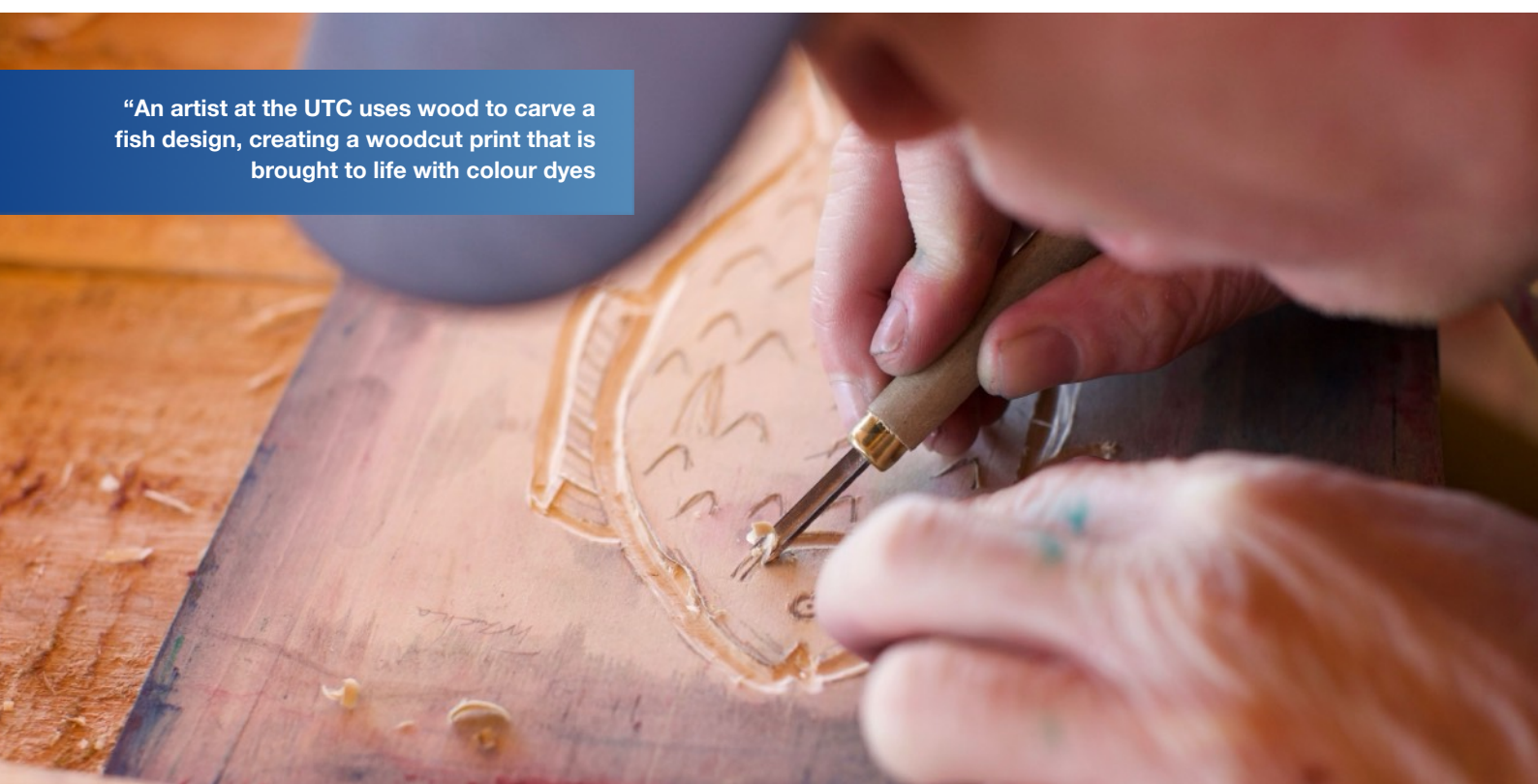
Indicator	Tanzania 2024
People with albinism receiving ongoing skills development or income generation support	58
Community members benefitting from the Umoja Training Centre (UTC)	15,927
Number of school children reached by the UTC	21,728
UTC tailors trained	18
Hats produced by UTC tailors	17,676
Hats produced since initiative begun (2021)	42,865

Since its establishment by Standing Voice in 2014, the Umoja Training Centre (UTC) on Ukerewe Island has grown into a thriving hub for inclusion, skills development, and community transformation. Designed to support people with albinism and their families, many of whom have been excluded from education and employment, the UTC offers a safe and vibrant space for learning, healing, and empowerment.

The UTC remains home to the Ukerewe Albinism Society and serves as a focal point for a growing network of community-based organisations and peer support groups. In 2024, the Centre continued to deliver life-changing opportunities for education, economic empowerment and inclusion through a broad range of formal training programmes, arts and cultural activities, and therapeutic support for survivors of discrimination and violence.

With the only public library on Ukerewe Island and a dynamic school outreach programme, the UTC plays a vital role in raising awareness of albinism and promoting inclusive education at the grassroots level. This year, the UTC supported the capacity development of numerous community groups and 58 individual trainees with albinism and their family members, offering practical training in: Tailoring, Soap-making, Batik, Radio production, Performing and visual arts, Music and storytelling

With the support of the Pierre Fabre Foundation and Croda Foundation, the Tunajitambua tailoring initiative was able to continue scaling its impact, with UTC-trained artisans producing 17,676 wide-brimmed sun hats distributed free across 278 hospitals and health centres in Tanzania and Malawi. These protective hats form a vital part of Standing Voice's Skin Cancer Prevention Programme (SCPP), helping individuals with albinism manage sun exposure and reduce cancer risk. 15,927 people from across Ukerewe Island were directly engaged by UTC activities in 2024, through training sessions, community outreach, education campaigns, and public events, affirming the Centre's status as a beacon of inclusion and empowerment on the Island.



“An artist at the UTC uses wood to carve a fish design, creating a woodcut print that is brought to life with colour dyes

## 6.6 Human Rights Training

A central goal of our Social Protection and Welfare Programme is to strengthen the capacity of key duty bearers to recognise, uphold, and monitor the human rights of people with albinism across communities in Tanzania and Malawi. Through targeted workshops for community based advocates, and clinic-based awareness seminars, we are building a growing network of albinism ambassadors, including family members, healthcare and welfare professionals, educators, local government officials, law enforcement, members of the judiciary, national human rights institutions, media representatives, religious and traditional leaders, and albinism association leaders.

In 2024, this area of work expanded further in Malawi through the Pierre Fabre Foundation and the European Commission co-funded Ufulu Wanga project, delivered in collaboration with YONECO and Beyond Suncare. This partnership has driving systemic change by embedding human rights protections into local structures and services, and by empowering communities to become agents of inclusion and accountability.

➔ **People with albinism and family members participating in rights-based training: 17,217**

Operating through dermatology clinics, the First Response Team delivered human rights training to thousands of people with albinism and their families and caregivers. The team leads educational seminars and distributes resources to build understanding of albinism and human rights and raises awareness of best practices for protecting and empowering families impacted by albinism.

By the end of 2024, 17,217 people had received this right-based training at clinics, 12,122 of these people were in Tanzania and 5,149 in Malawi.

➔ **Albinism Advocates trained: 261**

In 2024, we expanded our efforts in training a network of community based albinism advocates to mobilise, monitor and support the most at-risk people with albinism at the community level. These advocates included albinism association leaders, social welfare professionals and community health workers, many of whom are already engaged in the SCPP and play a critical role in the identification, mobilisation and ongoing care of people with albinism in their communities.

During the reporting period 261 Albinism Advocates were trained and equipped to support and advocate for the rights of persons with albinism in communities across Tanzania and Malawi.



➔ Human rights seminars took place in both formal training and clinical settings in both Tanzania and Malawi

## 6.7 Women's Albinism Action Group: Empowering Women, Confronting Stigma

Women with albinism, and mothers of children with albinism, face compounded and intersecting forms of discrimination, rooted in gender, disability, and social stigma. In Sub-Saharan Africa, harmful myths persist, including the belief that sexual intercourse with a woman with albinism can cure infertility or HIV/AIDS. These dangerous misconceptions place women at heightened risk of sexual violence, coercion, and HIV infection. Meanwhile, mothers of babies born with albinism are frequently blamed and stigmatised, abandoned by their partners and families, and left solely responsible for their child's wellbeing. This not only increases their emotional and economic burden but also limits opportunities for income generation, exacerbating poverty and placing both mother and child in greater vulnerability.

In response, the Women's Albinism Action Group (WAAG) was founded in 2015 with the support of Standing Voice. Today, WAAG is a registered community-based organisation, led by and for women impacted by albinism. Based at the Umoja Training Centre on Ukerewe Island, the group began as an informal peer network and has since evolved into a powerful collective of change-makers advocating for dignity, inclusion, and justice for other mothers and their families.

WAAG provides a safe space for women to share experiences, build solidarity, and mobilise around shared goals. The group works in close partnership with Standing Voice and the Tanzania Albinism Society, offering peer counselling to new mothers of children with albinism via the Skin Cancer Prevention Programme's clinical network, and conducts home visits and outreach in communities where stigma remains entrenched. Members travel widely to raise awareness, challenge myths, interrupt abandonment, promote positive narratives, particularly through direct engagement directly with families, in schools, health centres, and other public forums.

Over the past year, WAAG has reached 10,228 individuals through its community outreach events designed to deepen public understanding of albinism. In 2024 the WAAG worked with Standing Voice to provide peer-to-peer counselling for 132 women and girls attending dermatology clinics, and delivered ongoing psychosocial support through regular home visits to 19 women and their families on Ukerewe Island. WAAG's community support helpline received 969 calls in 2024. Since its launch in 2022, the helpline has provided vital over-the-phone counselling and advice to women on Ukerewe, with a total of 2,764 calls handled to date.

The WAAG plays a critical frontline role in protecting the rights, health, and wellbeing of women and families impacted by albinism. Through their leadership, lived experience, and collective voice, the women of WAAG are transforming attitudes and forging new pathways to safety, equality, and empowerment.



- ➔ **Established at the UTC** as a safety and support group for women impacted by albinism
- ➔ The WAAG registered as a **community-based organisation in 2021**
- ➔ The WAAG provides **peer counselling** and operates a **helpline** for women and mothers impacted by albinism; delivers **albinism training for welfare professionals**; and conducts **community outreach** to build public awareness of the rights and needs of people with albinism
- ➔ The WAAG has sensitised **22,433** people on albinism since 2021

## 7. SPECIAL EVENTS

In 2024, Standing Voice expanded its visibility and influence by participating in prominent international events while hosting significant national activities to commemorate key milestones and advocacy dates. Throughout the year, our staff were invited to speak at international conferences, workshops, and symposia, showcasing our work and strengthening alliances across the global albinism and health sectors.

In March, Bonface Massah, Executive Director of Standing Voice Malawi, attended a high-level meeting on albinism convened by the Government of Malawi in Lilongwe. This event brought together leading stakeholders committed to advancing the rights and welfare of people with albinism, with a particular focus on renewing Malawi's National Action Plan on Albinism.

In April, Robi Matiaga, Monitoring, Evaluation and Learning Manager for Standing Voice Tanzania, participated in GlobalSkin's inaugural Africa Regional Members Meeting held in Nairobi, Kenya. This landmark gathering convened over 35 patient organisations from 13 African countries to build a stronger, united network of dermatology patient advocates across the continent. Robi delivered a presentation highlighting lessons learned and impact from Standing Voice's health programmes in Tanzania and Malawi.

In May, Chikondi Kanjadza, Protection and Welfare Officer at Standing Voice Malawi, took part in the Women's Learning Forum hosted by the African Albinism Network (AAN), also in Nairobi. This unique forum brought together women leaders from across Africa, strengthening their ability to defend human rights within the albinism movement and equipping them with the tools and confidence to advocate for improved healthcare, protection, and inclusion in their communities.

In June and July, Standing Voice hosted a series of activities across Tanzania and Malawi to mark International Albinism Awareness Day (IAAD) and World Skin Health Day (WSHD). These included free dermatology and low vision screenings in Tanzania's Pwani Region, as well as a public event in Rhumpi, Malawi to honour IAAD. To mark the first officially recognised World Skin Health Day 2025, Standing Voice hosted a special event in Mbeya and Iringa, Tanzania, with support from the International League of Dermatology Societies (ILDS), the International Society of Dermatology (ISD), and CerVe. The event was attended by officials from the Ministry of Health and representatives from the Regional Dermatology Training Centre.

In August and September, we were honoured to welcome Antoine Gliksohn, Executive Director of the Global Albinism Alliance, on a joint visit to Tanzania and Malawi. During his time in the region, Mr. Gliksohn visited project sites, engaged with survivors of trauma and skin cancer, attended training sessions, and participated in a local radio broadcast to share insights from his global advocacy work. In the same period, we also hosted staff delegations from two of our key partners, the Pierre Fabre Foundation and Munuli Ryco. These visits offered important opportunities to showcase the impact of our work and to strengthen strategic collaborations in support of people with albinism.

Throughout the year, Standing Voice also organised national media activities to mark Skin Cancer Awareness Month and World Sight Day. We welcomed high-level visits from representatives of the President's Office (TAMISEMI), the Prime Minister's Office, and the Ministry of Health, including the National Eye Coordinator, as well as regional and district education officials in Tanzania and Malawi. We were also hosted leaders from the Tanzania Albinism Society (TAS) and the Association of Persons with Albinism in Malawi (APAM), and reinforced our shared commitment to rights-based change. These engagements received widespread coverage across television, radio, and print media, helping to raise public awareness and build momentum for greater inclusion and protection of people with albinism.



## 8. DATA MANAGEMENT

In 2024, we enhanced our digital health infrastructure through the continued development and deployment of a custom-built electronic health information system built with Commcare. The platform remained fully operational across the year, underpinning the delivery of core services under the Skin Cancer Prevention Programme (SCPP) and the Vision and Education Programme (VEP) in both Tanzania and Malawi. It also continued to support data management for a third-party albinism initiative in Rwanda, in partnership with Health Alert Organisation.

In line with our commitment to holistic care, we designed and piloted new digital tool to support the Welfare and Social Protection Programme, including a risk assessment form for use during clinic peer counselling sessions. These tools were initially tested on paper during the first half of year, then later built into the Commcare system and tested. Full integration of the form into CommCare is scheduled for the start of 2025.

To meet growing service demands, and to replace old tablets, through the support of the Pierre Fabre Foundation we procured 40 additional tablets during the reporting period, expanding our digital capacity across both countries for the next phase of expansion under the partnership.

Digital health training remained a priority throughout the year. Standing Voice delivered targeted CommCare training to a wide range of health professionals, including newly enrolled dermato-venereology officers, clinical officers, medical assistants, optometrists, and programme staff. By the year's end, 234 personnel had been trained to use the platform in the field, ensuring more accurate, real-time data collection and more responsive care for people with albinism.

	No. of people trained
<b>Tanzania</b>	80
<b>Malawi</b>	154
<b>Total</b>	<b>234</b>



## 9. FUNDING MATTERS

### GRANT-MAKING POLICY

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Standing Voice provides grants to collaborating organisations that require funding to deliver services aligned with our mission. In some cases, the trustees may award grants to independent organisations not in formal partnership with Standing Voice, where there is clear alignment with our charitable objectives.

Grants are directed toward organisations or services that promote the wellbeing and social inclusion of people with albinism in Africa, particularly through initiatives in health, education, welfare, and community development. All grants are subject to strict conditions, including robust financial reporting and accounting standards, strong internal policies (covering safeguarding, finance, and procurement), a proven track record of successful implementation, and full compliance with relevant regulations and international standards, as outlined in Standing Voice's grant agreements.

### FUNDRAISING ACTIVITIES IN THE UK

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Standing Voice raises funds from a diverse portfolio of sources, including trust funds, grant-giving foundations and institutions, corporate donors, and individual philanthropists. Additional support is generated through public donations, direct appeals, and organised fundraising events and campaigns. In 2024, our principal sources of funding continued to be grants from charitable foundations and trusts, alongside generous contributions from individuals, corporate partners, and the wider public.

We are proud to have been supported throughout 2024 by a wide range of innovative and committed funders. These include the Pierre Fabre Foundation (PFF), the European Commission (EU), the International Foundation for Dermatology (IFD), the International League of Dermatological Societies (ILDS), the United Nations Voluntary Fund for Victims of Torture (UNVFVT), Deloitte Community Fund, the Bilton Charitable Foundation, the John Armitage Charitable Trust (JACT), the HCD Memorial Fund, Inside the Same, The Edge, Wings of Support, the Irish Global Health Network, Global Green Grants, Glasgow University, Manuli Ryco, the Evan Cornish Foundation, the Souter Charitable Trust, and the Reed Foundation. We are also deeply grateful for the extensive in-kind support received from Altruist, the African Albinism Foundation, and ISDIN, along with many other generous partners, including those who have chosen to remain anonymous.

The trustees extend their heartfelt thanks to all donors and funding partners for their invaluable support, which continues to make our work possible and meaningful. Your commitment enables us to protect, empower and include people with albinism across Tanzania, Malawi, and beyond.

### FINANCIAL PERFORMANCE

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Income during the period 1st January 2024 to 31st December 2024 amounted to £1,427,928 (January 2023–December 2023: £1,192,750). Voluntary income for 2024 was £1,421,263 (2023: £1,184,639). Of the total income, £1,320,521 (2023: £1,110,711) was restricted and £107,407 (2023: £82,039) was unrestricted. The restricted income consists of donated funds from grant funders and individuals, as well as restricted gift in-kind support amounting the value of £128,182. £603,436 (2023: £484,658) of restricted funding was carried forward. Unrestricted income was mainly from individual donations.

Expenditure amounted to £1,269,270 (2023: £1,070,753) of which £1,207,693 (2023: £1,008,458) was project expenditure, £57,301 (2023: £47,505) was fundraising expenditure and £4,276 (2023: £14,790,) was governance costs. Of the total expenditure, 1,201,744 (2023: £1,003,165) was restricted expenditure and £67,526 (2023: £67,588) was unrestricted expenditure. Standing Voice exercises a policy of setting aside funds to cover 6 months of administration overheads as reserves (£182,485), to cover core costs in the event of the organisation encountering a period of reduced income. The charity free reserves at the year were £114,690.

At the end of the financial year ending 31st December 2024, the charity carried forward a balance of £718,126 (2023: £559,468), of which £182,485 was available for salaries and overheads. The organisation also awaited funding responses from major grant funders. The trustees deemed reserve funds held to be sufficient, keeping in consideration the overheads budget allocations in restricted funds held, and the status of committed funding from new and existing donors due for disbursement in 2025 amounting to over £1,150,000.

## EXPENDITURE SUPPORTING KEY OBJECTIVES

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Standing Voice has been able to increase expenditure towards its life saving programmes in 2024 to £1,269,270 (£1,070,753 in 2023). This has been vital when our clients' needs remain under pressure due to unstable global economic conditions, forthcoming elections in both Tanzania and Malawi, increasing risk of climate change-related disasters, and continued threat of attack against people with albinism. This increase in project expenditure (£198,517 increase on 2023) has been carefully planned and deemed viable based on holding and securing new multi-year funding partnerships in 2024. Expenditure on our projects promoting the wellbeing and social inclusion of people with albinism is consistent with Standing Voice's objectives as defined in its governing constitution.

People with albinism in Tanzania and Malawi continue to benefit from capacity development; improved dermatological and ophthalmological health services; innovative trauma recovery interventions; increased access to education; and positive advances in local and international awareness on albinism resulting from Standing Voice's project activity. Additionally, through training and coordination of health, social care and education service providers we are building a sustained, scalable and locally driven response to this issue in both countries.

The charity's projects this year have grown substantially both in terms of geographical reach, and depth of the interventions being delivered across both countries of operation. Whilst growing the footprint of its work Standing Voice is progressively interlinking services, to ensure individual projects act as gateways for other essential services. Scaling up geographical reach, alongside investing in a holistic approach to our work has led Standing Voice to achieve its objective of combating human rights abuses against people with albinism by further advancing integration in society in 2024.



## 10. GOVERNANCE AND RISK

### FUTURE PLANS OF THE CHARITY

In 2025, Standing Voice will expand the reach and impact of its core programmes, enhancing access to dermatology, eye care, psychosocial support, and livelihoods services for thousands of underserved people with albinism and their families in Tanzania and Malawi. We will continue to scale our training initiatives, empowering community leaders, teachers, health professionals, and civil society groups to build an informed and responsive society that champions the rights and inclusion of persons with albinism.

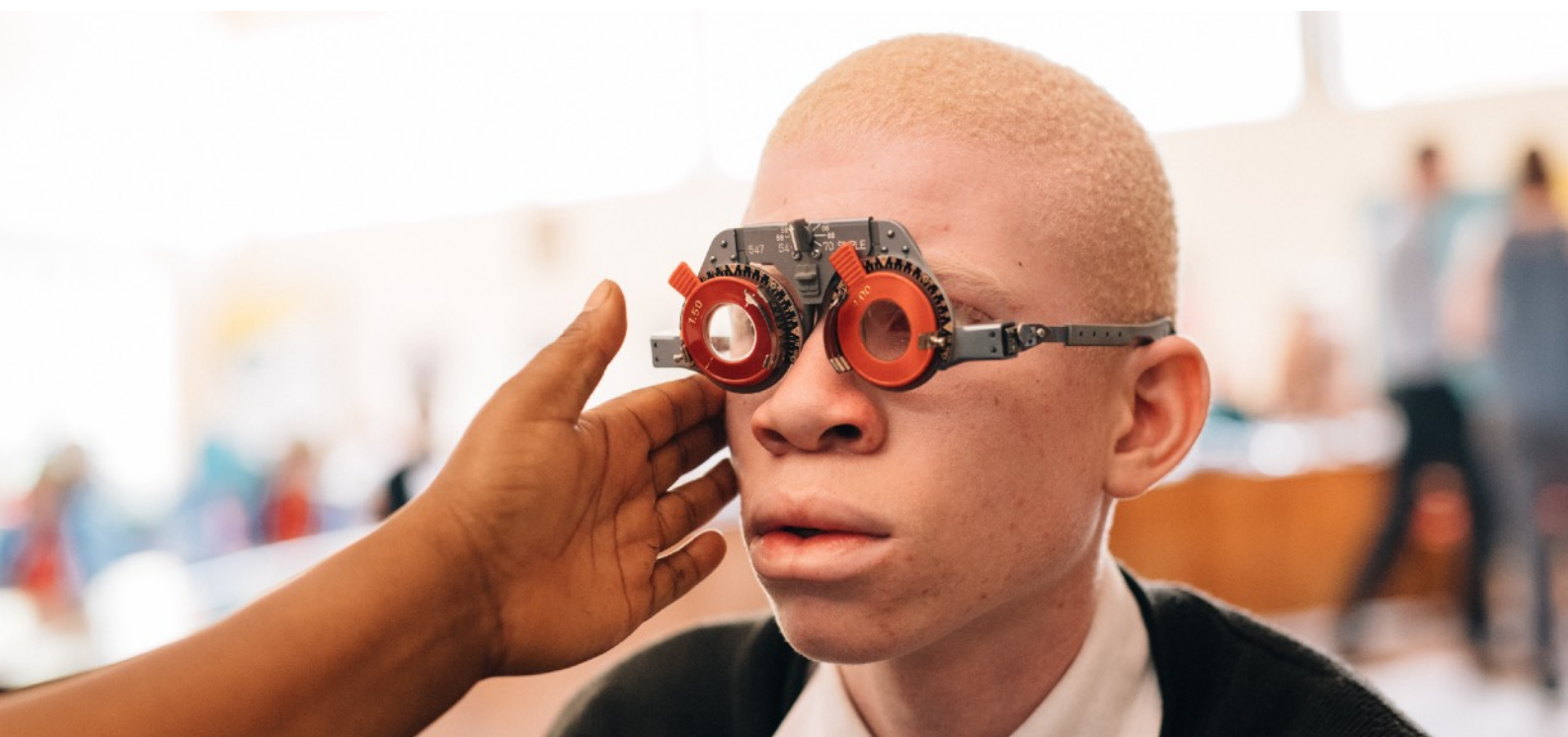
In January 2025, we will begin a new partnership with Inside the Same and Mama Mzungu to produce disposable sanitary pads, which will be distributed for free to thousands of women and girls across Tanzania through the Skin Cancer Prevention Programmes Clinical network.

In April in Malawi, we will launch the Tutakilane Initiative, a new European Commission-funded project that builds on the progress of the Ufulu Wanga Project. While Ufulu Wanga focused on healthcare, human rights and protection, Tutakilane will shift the focus toward economic empowerment, expanding access to vocational training, employment opportunities, and sustainable livelihoods for people with albinism.

In both countries, 2025 will mark a period of consolidation and growth. We will expand and strengthen our service delivery while intensifying advocacy to promote long-term sustainability. In Tanzania, we will leverage the recently adopted National Action Plan (NAP) on Albinism, and advocate for its renewal in Malawi, to deepen government ownership of the Skin Cancer Prevention Programme (SCPP). This will include forming a national task force with Tanzania's Ministry of Health to develop a Quality Assurance Tool, designed to help integrate the SCPP into the national health system and establish clear, government-led mechanisms for monitoring programme quality and performance.

We are also excited to extend our support beyond Tanzania and Malawi, by initiating collaborations with albinism organisations in Zimbabwe, Uganda, and Rwanda. By sharing over 15 years of insights and experience from implementing the SCPP model, we aim to strengthen local initiatives and accelerate progress in these countries.

In October 2025, Standing Voice will co-host the first-ever World Forum on Skin Cancer Prevention and Management for Persons with Albinism, in partnership with the International League of Dermatological Societies (ILDS) and the Global Albinism Alliance. This landmark event will convene leading health professionals, albinism advocates, and funders from around the world to develop a coordinated global action plan to end the skin cancer crisis disproportionately affecting this population.



## RISK

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### Risk Management

The primary risk to Standing Voice, and, by extension, the communities we serve, is limited staff capacity to meet the growing scale and complexity of our programmes. As we deepen our work and expand our programmes, we continue to uncover the diverse and interconnected challenges faced by people with albinism. Addressing these evolving needs requires sustained investment in a skilled, adaptable, and well-supported team.

We mitigate this risk through a diversified funding portfolio and the continuous pursuit of new grant opportunities. We also closely monitor our expenditure pipeline to ensure strategic recruitment and workforce planning can be aligned with programme growth and donor timelines.

To guard against operational risks, including maladministration, we maintain strong governance and oversight systems across all areas of our work in Tanzania and Malawi. These include regular monitoring and evaluation processes, robust internal controls, and comprehensive financial and programme reporting. All fund disbursements are subject to detailed review and authorisation by Standing Voice UK management.

Executive Management in the UK oversees all international fund transfers through a two-step foreign exchange approval process, which requires dual sign-off from authorised administrators. In addition, UK-based leadership and trustees conduct regular site visits to offices, partners, and project locations, helping to strengthen accountability and proactively identify and address emerging risks.

### Additional Risks

Other risks facing the organisation include:

- **Political and regulatory instability:** Changes in government policy or banking regulations, particularly regarding foreign currency, can impact our ability to transfer and manage funds efficiently.
- **Security threats:** In some regions, heightened security risks may affect the safe delivery of services or the wellbeing of staff and beneficiaries.
- **Donor dependency:** Over-reliance on a small number of key funders may pose sustainability risks in the event of funding cuts or shifts in donor priorities.
- **Technological limitations:** In areas with limited infrastructure, challenges related to internet access and data management may hinder communication, reporting, and implementation of digital tools like our CRM system.
- **Climate-related disruptions:** Extreme weather or environmental changes can impact access to project sites, disrupt community outreach, or exacerbate health vulnerabilities among our beneficiaries.

We remain committed to identifying, monitoring, and mitigating these and other risks as part of our ongoing responsibility to safeguard the effectiveness, integrity, and sustainability of our work.

## RESPONSIBILITIES OF THE BOARD OF TRUSTEES

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The Trustees are responsible for managing the affairs of the CIO and may for that purpose exercise all the powers of the CIO.

It is the duty of each charity trustee:

1. to exercise his or her powers and to perform his or her functions in his or her capacity as a trustee of the CIO in the way he or she decides in good faith would be most likely to further the purposes of the CIO; and
2. to exercise, in the performance of those functions, such care and skill as is reasonable in the circumstances having regard in particular to:
  1. any special knowledge or experience that he or she has or holds himself or herself out as having; and,
  2. if he or she acts as a charity trustee of the CIO in the course of a business or profession, to any special knowledge or experience that it is reasonable to expect of a person acting in the course of that kind of business or profession.

The Board of Trustees are responsible for complying with the requirements of the Charities Act 2011 with regard to the keeping of accounting records, to the preparation and scrutiny of statements of account, and to the preparation of annual reports and returns for submission to the Charity Commission.

## PUBLIC BENEFIT

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In accordance with section 17 of the Charities Act 2011 the Trustees confirm that they have had regard to the Charity Commission's guidance in relation to public benefit. The Trustees have referred to the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning the charity's future activities. In particular, the Trustees have considered how planned activities contribute to the aims and objectives they have set.

## TRUSTEES' DECLARATION

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There is no relevant information of which the auditor is unaware. Each Trustee has taken all the necessary steps that he/she ought to have taken as a Trustee in order to inform themselves of all relevant information, and to establish that the auditor is aware of that information.

Approved by the Board of Trustees and signed on its behalf by:



Chair of the Board of Trustees  
5/04/2025



## 11. ACCOUNTS

### 11.1 Independent Auditor's Report to the Trustees of Standing Voice (UK)

#### Opinion

We have audited the financial statements of Standing Voice (UK) (the 'CIO') for the year ended 31 December 2024 which comprise the Statement of Financial Activities, the Balance Sheet and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the CIO's affairs as at 31 December 2024, and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

#### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the CIO in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

#### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

## **Other information**

The trustees are responsible for the other information. The other information comprises the information included in the trustees' report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

## **Matters on which we are required to report by exception**

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the financial statements is inconsistent in any material respect with the trustees' report; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit.

## **Responsibilities of trustees**

As explained more fully in the trustees' responsibilities statement in trustees' report, the trustees are responsible for the preparation of financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the CIO's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the CIO or to cease operations, or have no realistic alternative but to do so.

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with regulations made under section 154 of that Act.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- We obtained an understanding of the legal and regulatory frameworks that are applicable to the CIO and determined that the most significant are the Statement of Recommended Practice 'Accounting and Reporting by Charities' (SORP 2019), in accordance with the Financial Reporting Standard applicable in the UK (FRS 102) applicable to smaller entities and the Charities Act 2011.
- We understood how the CIO is complying with those frameworks via communication with those charged with governance, together with the review of the CIO's documented policies and procedures.
- The audit team, which is experienced in the audit of charities, considered the charity's susceptibility to material misstatement and how fraud may occur. Our considerations included the risk of management override.
- Our approach was to check that the income from grants and donations was properly identified, related expenditure was appropriately charged in accordance with any restrictions that may have been in place and that payments overseas were made to valid organisations. This included reviewing journal adjustments and unusual transactions.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.

### Use of our report

This report is made solely to the CIO's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the CIO's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the CIO and the CIO's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



**Knox Cropper LLP**  
**Statutory Auditor**  
**65 Leadenhall Street**  
**London**  
**EC3A 2AD**

*Knox Cropper LLP is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.*

31 October 2025

## 11.2 Statement of Financial Activities (SoFA)

Statement of Financial Activities (Incorporating an Income and Expenditure Account) for the period ended 31 December 2024:

	Notes	Unrestricted funds (£)	Restricted income funds (£)	Total 2024 (£)	Total 2023 (£)
<b>Income and endowments from:</b>					
Donations and legacies		100,742	1,320,521	£1,421,263	1,184,639
Income from investments		6,665	-	6,665	3,111
Other income		-	-	-	5,000
<b>Total income and endowments</b>	<b>2</b>	<b>107,407</b>	<b>1,320,521</b>	<b>1,427,928</b>	<b>1,192,750</b>
<b>Expenditure on:</b>					
Raising funds		2,865	54,436	57,301	47,505
Charitable activities		60,385	1,147,308	1,207,693	1,008,458
Other expenditure		4,276	-	4,276	14,790
<b>Total expenditure</b>	<b>3</b>	<b>67,526</b>	<b>1,201,744</b>	<b>1,269,270</b>	<b>1,070,753</b>
<b>Net income/(expenditure) and net movement in funds for the year</b>		<b>39,881</b>	<b>118,777</b>	<b>158,658</b>	<b>121,997</b>
<b>Net income/(expenditure) before other recognised gains/(losses)</b>		<b>39,881</b>	<b>118,777</b>	<b>158,658</b>	<b>121,997</b>
<b>Net income/(expenditure) and movement in funds for the year</b>		<b>39,881</b>	<b>118,777</b>	<b>158,658</b>	<b>121,997</b>
<b>Total funds brought forward</b>		<b>74,809</b>	<b>484,659</b>	<b>559,468</b>	<b>437,470</b>
<b>Total funds carried forward</b>		<b>114,690</b>	<b>603,436</b>	<b>718,126</b>	<b>559,467</b>

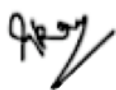
The Statement of Financial Activities includes all gains and losses recognised in the year. All the activities derive from continuing operations during the above periods.

## 11.3 BALANCE SHEET

Balance Sheet as at 31 December 2024

	Notes	Unrestricted funds (£)	Restricted income funds (£)	December 2024 (£)	December 2023 (£)
<b>Fixed assets</b>					
Tangible investments	4	-	40,573	40,573	29,507
Intangible investments					
<b>Total fixed assets</b>		<b>-</b>	<b>40,573</b>	<b>40,573</b>	<b>29,508</b>
<b>Current assets</b>					
Debtors and prepayments	5	43,997	-	43,997	25,519
Cash at bank and in hand		80,473	581,368	661,841	543,041
<b>Total current assets</b>		<b>124,470</b>	<b>470,697</b>	<b>705,838</b>	<b>568,560</b>
<b>Liabilities</b>					
Creditors: amounts falling due within one year	6	9,780	18,505	28,285	38,600
<b>Net current assets/(liabilities)</b>		<b>114,690</b>	<b>562,863</b>	<b>677,553</b>	<b>529,960</b>
<b>Total assets less current liabilities</b>		<b>114,690</b>	<b>603,436</b>	<b>718,126</b>	<b>559,468</b>
<b>Net assets</b>		<b>114,690</b>	<b>603,436</b>	<b>718,126</b>	<b>559,468</b>
<b>Funds of the charity</b>					
Unrestricted funds		114,690	-	114,690	74,809
Restricted income funds	7	-	603,436	603,436	484,659
Endowment funds		-	-	-	-
<b>Total funds</b>		<b>114,690</b>	<b>603,436</b>	<b>718,126</b>	<b>559,468</b>

The financial statements were approved and authorised for issue by the Trustees on 28/04/2024 and signed on their behalf by:



**Gurmeet Kaur**

Treasurer of the Board of Trustee

## BASIS OF PREPARATION

Basis of preparation and accounting policies for year ended 31 December 2024

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) – Charities SORP (FRS 102), and the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

### 1. ACCOUNTING POLICIES

*This list of accounting policies has been applied by the charity.*

Incoming Resources	
<b>Recognition of incoming resources</b>	These are included in the Statement of Financial Activities (SoFA) when: <ul style="list-style-type: none"> <li>- the charity becomes entitled to the resources;</li> <li>- the trustees are virtually certain they will receive the resources; and</li> <li>- the monetary value can be measured with sufficient reliability</li> </ul>
<b>Incoming resources with related expenditure</b>	Where incoming resources have related expenditure (as with fundraising or contract income) the incoming resources and related expenditure are reported gross in the SoFA.
<b>Grants and donations</b>	Grants and donations are only included in the SoFA when the charity has unconditional entitlement to the resources.
<b>Tax reclaims on donations and gifts</b>	Incoming resources from tax reclaims are included in the SoFA at the same time as the gift to which they relate.
<b>Contractual income and performance-related grants</b>	This is only included in the SoFA once the related goods or services have been delivered.
<b>Gifts in kind</b>	Gifts in kind are accounted for at a reasonable estimate of their value to the charity or the amount actually realised. Gifts in kind for sale or distribution are included in the accounts as gifts only when sold or distributed by the charity. Gifts in kind for use by the charity are included in the SoFA as incoming resources when receivable.
<b>Donated services and facilities</b>	These are only included in incoming resources (with an equivalent amount in resources expended) where the benefit to the charity is reasonably quantifiable, measurable and material. The value placed on these resources is the estimated value to the charity of the service or facility received.
<b>Volunteer help</b>	The value of any voluntary help received is not included in the accounts but is described in the trustees' annual report.
<b>Investment income</b>	This is included in the accounts when receivable.
<b>Investment gains and losses</b>	This includes any gain or loss on the sale of investments and any gain or loss resulting from revaluing investments to market value at the end of the year.

## Expenditure and Liabilities

<b>Liability recognition</b>	Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to pay out resources.
<b>Governance costs</b>	Include costs of the preparation and audit of statutory accounts, the costs of trustee meetings and cost of any legal advice to trustees on governance or constitutional matters.
<b>Grants with performance conditions</b>	Where the charity gives a grant with conditions for its payment being a specific level of service or output to be provided, such grants are only recognised in the SoFA once the recipient of the grant has provided the specified service or output.
<b>Grants payable without performance conditions</b>	These are only recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the charity.
<b>Support Costs</b>	Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, e.g. allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

## Assets

<b>Tangible fixed assets for use by charity</b>	These are capitalised if they can be used for more than one year, and cost at least £5,000. They are valued at cost or a reasonable value on receipt.
<b>Investments</b>	Investments quoted on a recognised stock exchange are valued at market value at the year-end. Other investment assets are included at trustees' best estimate of market value.
<b>Stocks and work in progress</b>	These are valued at the lower of cost or market value.

## 2. ANALYSIS OF INCOME AND ENDOWMENTS

Analysis		2024 (£)	2023 (£)
<b>Donations and Legacies</b>	Restricted income	1,320,521	1,110,711.00
	Unrestricted income	100,742	73,928.00
		<b>1,421,263</b>	<b>1,184,639.00</b>
<b>Income from investments</b>	Bank interest	6,665	3,111.00
		6,665	3,111.00
<b>Total income and endowments</b>		<b>1,427,928</b>	<b>1,187,750.00</b>

### 3. ANALYSIS OF RESOURCES EXPENDED

Analysis		2024 (£)	2023 (£)
<b>Costs of generating voluntary income</b>	Staff costs	45,063	37,299
	Support costs	12,239	10,206
		<b>57,301</b>	<b>47,505</b>
<b>Charitable activities</b>	Staff costs	180,250	149,196
	Support costs	48,956	40,823
	Direct project costs	978,487	818,439
		<b>1,207,693</b>	<b>1,008,458</b>
<b>Governance costs</b>	Auditors fee	2,650	12,840
	Accounting advice & payroll services	1,600	1,950
		<b>4,276</b>	<b>14,790</b>
<b>Total</b>		<b>1,269,270</b>	<b>1,070,753</b>

### 4. TANGIBLE FIXED ASSETS

	Freehold land and buildings (£)	Other land and buildings (£)	Plant, machinery and motor vehicles (£)	Fixtures, fittings and equipment (£)	Total (£)
<b>Cost</b>			14,608		14,608
At 1 January 2024	-	-	31,594	-	31,594.00
Additions	-	-	24,956.16	-	24,956.16
At 31 December 2023	-	-	71,158.16	-	71,158.16
<b>Depreciation</b>					
At 1 January 2024	-	-	16,695.11	-	16,695.11
Charge for the year	-	-	13,889.77	-	13,889.77
At 31 December 2024	-	-	30,584.88	-	30,584.88
<b>Net Book Value</b>					
At 31 December 2024	-	-	40,573.28	-	40,573.28
At 1 January 2024	-	-	54,463.05	-	54,463.05

## 5. DEBTORS AND PREPAYMENTS

Analysis of debtors	Amounts falling due within one year (£)		Amounts falling due after more than one year (£)	
	2024	2023	2024	2023
Prepayments and accrued income	43,997	25,519	-	-
<b>Total</b>	<b>43,997</b>	<b>25,519</b>	-	-

## 6. CREDITORS AND ACCRUALS

Analysis of creditors	Amounts falling due within one year (£)		Amounts falling due after more than one year (£)	
	2024	2023	2024	2023
Other creditors	5,904.11	7,014.00	-	-
Accruals and deferred income	22,381.30	31,586.00	-	-
<b>Total</b>	<b>28,285.41</b>	<b>38,600.00</b>	-	-

## 7. RESTRICTED FUNDS

Fund Name	Purpose and Restrictions
<b>Skin Cancer Prevention</b>	Skin cancer prevention services for people with albinism in Tanzania and Malawi
<b>Research</b>	Research into access to health for people with albinism in Tanzania
<b>Awareness Raising</b>	Creating and promoting positive imagery of people with albinism in Africa to raise awareness
<b>Vision and Education Programme</b>	Low Vision services and promotion of education for people with albinism in Tanzania and Malawi
<b>Umoja Children Centre</b>	Building of a centre for learning and healing for children with albinism in Tanzania
<b>Malawi Operations</b>	Operational overheads for Standing Voice's team based in Lilongwe
<b>Welfare Programme</b>	Psychosocial support and material assistance for survivors of abuse



### Movement of major funds:

Fund names	Fund balances brought forward 1 January 2024 (£)	Restricted Incoming resources (£)	Restricted outgoing resources (£)	Transfers (£)	Gains and losses (£)	Fund balances carried forward 31 December 2024 (£)
Skin Cancer Prevention	16,889	878,187	775,951	-	-	119,125
Advocacy and Awareness	50,239	40,629	30,739	-	-	60,128
Vision and Education	-3,593	120,363	113,653	-	-	3,117
Umoja Children's Centre	138,091	21,250	13,942	-	-	145,399
Welfare & Livelihoods services	55,871	91,707	121,782	-	-	25,796
Core Costs	227,162	168,384	145,677	-	-	249,869
<b>Total Restricted Funds</b>	<b>484,659</b>	<b>1,320,521</b>	<b>1,201,744</b>	<b>-</b>	<b>-</b>	<b>603,434</b>

### 9. DETAILS OF CERTAIN ITEMS OF EXPENDITURE

Fees for examination of the accounts	2024 (£)	2023 (£)
Auditor's fees for reporting on the accounts	13,380	12,840
Other fees (for example: advice, consultancy, accountancy services) paid to the independent examiner or auditor	1,600	1,950

## Support costs:

Support Costs Type	Fundraising activity (£)	Charitable Activity (£)	Governance Activity (£)	Total Cost (£)
Building costs	6,759	27,038	-	33,797
Communications	1,395	5,581	-	6,976
Legal & professional	739	2,954	-	3,693
Other costs	423	1,691	-	2,114
Financial costs	145	580	-	724
Depreciation	2,778	11,112	-	13,890
<b>Total amount (£)</b>	<b>12,239</b>	<b>48,955</b>	<b>-</b>	<b>61,194</b>

## 10. GRANT-MAKING

Grants to individuals/institutions Purpose for which grants made	31 Dec 2024
	Total amount (£)
Beyond Suncare	17,246
Youth Net and Counselling (YONECO)	30,201
<b>Total amount (£)</b>	<b>47,447</b>

*There were no support costs associated with the charity's grant-making.*

## 11. STAFF COSTS

Staff costs	Unrestricted	Restricted	2024 (£)	2023 (£)
Gross wages, salaries and benefits in kind	40,685.97	162,743.88	203,429.85	165,357.00
Employer's National Insurance costs	3,422.19	13,688.77	17,110.96	17,275.00
Pension costs	954.38	3,817.51	4,771.89	3,863.00
<b>Total staff costs</b>	<b>45,062.54</b>	<b>180,250.16</b>	<b>225,312.70</b>	<b>186,495.00</b>



Average number of full-time equivalent employees in the year	2024	2023
<i>The parts of the charity in which the employees work:</i>		
Fundraising		2
Charitable activities	3	3
Governance	1	1
<b>Total</b>	<b>6</b>	<b>6</b>

## 12. TRANSACTIONS WITH RELATED PARTIES

Name of trustee or connected party	Legal authority (e.g. order, governing document)	Amounts paid or benefit value	
		2024 (£)	2023 (£)
Harry Freeland	Governing document	65,000	56,667
	Expenditure related to role as Executive Director	12,458	-

*There are no amounts owing to or from the charity's trustees or other related parties by the charity at the year end. All transactions undertaken by (or on behalf of) the charity in which a trustee or related party has a material interest have been disclosed in the Notes to the Accounts.*





**STANDING VOICE**

England & Wales - Charity number 1151250

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# Accounts

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# Annual Report and Accounts

## 2023



Registered with  
**FUNDRAISING  
REGULATOR**

Registered charity  
No.1151250

## FOREWORD

This year the charity's projects have grown substantially both in terms of geographical reach, and depth of the interventions being delivered. Whilst growing the footprint of our work we are progressively interlinking services, to ensure individual projects act as gateways for other essential services. Scaling up geographical reach, alongside investing in a holistic approach to our work is enabling us to achieve our objectives of combating human rights abuses against people with albinism by further advancing integration within society and improving access to services in 2023.

This year, we have further advanced our strategy of training health workers, community leaders, civil society groups and human rights defenders so they are better prepared to respond to the needs of people with albinism. Our Skin Cancer Prevention Programme (SCPP) is now providing life saving dermatological healthcare and education to 10,829 people with albinism across 206 hospitals and health centres in Tanzania and Malawi and is the largest programme of its type existing for persons with albinism in Africa today. Meanwhile our Vision and Education Programme (VEP) has also accelerated its expansion and is now accessible to 3,877 people in Tanzania and will be replicated in Malawi for the first time in 2024. The VEP has continued to drive forward our vision of a future where children with albinism are able to realise their full potential. To further support this mission in 2023 our team partnered with schools across Tanzania to deliver a teacher training programme. Through this programme 102 teachers were equipped with the skills and knowledge to meet the needs of students with albinism, while thousands of students and community members have been reached with awareness raising and education.

People with albinism continue to be targeted by violent attacks throughout Africa. As well as applying pressure to governments to take action, and raising awareness of these atrocities internationally, we are working hard to provide direct support to survivors so they can recover from trauma and rebuild their lives. Our team is at the forefront of this support, providing a package of tailored assistance to people with albinism who have suffered abuse including; urgent physical and mental healthcare, housing and home security measures, micro-finance and livelihood support, access to justice and facilitation of ongoing psychosocial support and counselling. We are also partnering and funding various community organisations such as the Mothers' Albinism Action Group: a fierce collective of advocates who are providing peer counselling to other mothers, children and families across their communities in Tanzania.

On behalf of everyone at Standing Voice we want to say a huge thank you for the continued support and collaboration of our long-term funders and technical partners; the Foundation Pierre Fabre, the United Nations Voluntary Fund For Victims of Torture, the International league of Dermatology Societies, International Foundation For Dermatology, the Bilton Foundation, the John Armitage Charitable Trust, Inside the Same, Esther Ireland, Souter Charitable Trust, Evans Cornish Foundation and the Mite Organisation. Thanks to the unwavering support of these partners we have been able to strengthen and expand our life saving work to new areas of Tanzania and Malawi this year. This has included scaling up Welfare and Security initiatives to support the most vulnerable and at-risk people with albinism we work with through strengthened access to our toll-free helplines and provision of direct counselling and tailored support services. We were also delighted to welcome the support of new funders in 2023, including the launch of a new two year partnership with the European Commission through the Ufulu Wanga Project (Our Rights), and through a new one year partnership with the Deloitte Community Fund. I'd also like to extend thanks to those funders and partners who wish to stay anonymous. Finally, thank you to all our staff, volunteers, supporters, partners and funders around the world who have contributed towards realising our aims this year. Without you, our work would not be possible.

Looking ahead, we remain committed to our mission of building a better world for persons with albinism, where their rights are universally upheld and all forms of discrimination are ended.

A handwritten signature in black ink, reading 'Sabine Zetteler'.

Sabine Zetteler  
Chair of the Board of Trustees  
28/04/2024

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## 1. LEGAL AND ADMINISTRATIVE INFORMATION

<i>Charity Name</i>	Standing Voice (UK)
<i>Charity No.</i>	No. 1151250 Charitable Incorporated Organisation (CIO)
<i>Administrative offices</i>	<p>Standing Voice UK          Unit 34b          Regent Studios          8 Andrews Road          London          E8 4QN</p> <p>Standing Voice Tanzania          P.O. BOX 1902          Isamilo, Mwanza          Tanzania</p> <p>Standing Voice Malawi          Area 14          Plot No.63          Lilongwe</p>
<i>Registered Addresses</i>	<p>49 Newick Road          London          E5 0RP</p> <p>P.O. BOX 180          Ukerewe Island, Mwanza          Tanzania</p> <p>Area 14          Plot No.63          Lilongwe</p>
<i>UK Board of Trustees</i>	Sabine Zetteler (Chair) Gurmeet Kaur (Treasurer) Innocentia Magijima Harry Freeland
<i>Malawi Board of Trustees</i>	Grace Malera Tadala Chinkwezule Jonathan Beale
<i>Tanzania Board of Trustees</i>	Katwale Magaga Ally Possi Martha Mganga Harry Freeland
<i>UK Administration</i>	Harry Freeland, Jonathan Beale, Sam Clarke, Alfred Thomas Giovanna Giuriolo, Ruth Ayarza. Supported by a growing team of dedicated volunteers

## 2. REPORT OF THE TRUSTEES

### 2.1 Constitution

Standing Voice (UK) was originally constituted under a Foundation Constitution that came into effect on 14th March 2013, on which date Standing Voice became registered as a Charitable Incorporated Organisation (CIO). The trustees are the only members of the CIO. If the CIO is wound up the members have no liability to contribute to its assets and no personal responsibility for settling its debts or liabilities.

### 2.2 Board of Trustees

Trustees are appointed by existing trustees through an electoral process. There may be no fewer than three trustees at any one time on the Board of Trustees. There are four at present, and we aim to expand the Board further during 2024.

Standing Voice trustees hold quarterly board meetings. The board also addresses governance matters as and when necessary, through e-mail or other means as necessary.

Decisions are made either at a meeting of the charity trustees, by resolution in writing or electronic form and agreed upon by all of the charity trustees. Agreements may comprise either a single document, or several documents containing the text of the resolution in like form to each of which one or more charity trustees has signified their agreement.

No decision shall be made at a trustee meeting unless a quorum is present at the time the decision is taken. The quorum is two charity trustees, or the number nearest to one third of the total number of charity trustees, whichever is greater, or such larger number as the charity trustees may decide from time to time.

In selecting trustees, consideration is given to the overall breadth of knowledge and experience required of the Board of Trustees. Candidates are typically interviewed by at least two existing trustees and nominations are then presented for approval to the board. Successful candidates, once appointed, receive appropriate documentation about the roles and responsibilities of being a Standing Voice trustee.

Standing Voice has three international boards: Standing Voice UK (4 members), Standing Voice Tanzania (4 members) and Standing Voice Malawi (3 members).

### 2.3 Advisory Board

The Standing Voice Board of Trustees is supported by an Advisory Board made up of 9 experts from 7 countries (Malawi, Tanzania, Togo, USA, UK, France and Ireland). This includes a wide range of expertise in the fields of public health, dermatology, ophthalmology, education, trauma recovery, genetics, general medicine and surgery, and in-depth knowledge on albinism.

The Advisory Board provides expert guidance to the UK Board of Trustees and staff management team, by advising on strategy, and informing the design and implementation of our programmes. The Advisory Board also works closely with Standing Voice's wider staff teams, with a primary focus on developing resources and training manuals, leading the delivery of clinical and surgical training, conducting research and publication, and identifying funding opportunities.

Our warmest thanks go to our Advisory Board; Our current Chair of the Board Dr Andrew Sharp, and members; Professor Daudi Mavura, Dr Kelvin Maponda, Professor Melissa Levin, Dr Mark Wheeler, Professor Bayaki Saka, Dr Patricia Lund, Professor Charlotte Baker and Mark Fish.

## 2.4 Organisational Structure

The UK Board of Trustees manages the governance affairs of the charity on a voluntary basis and meets as necessary for this purpose, at least once a quarter. Standing Voice's Malawi and Tanzania offices report to Standing Voice UK. Therefore, the UK Board has primary governance responsibility for all Standing Voice operations. UK Trustees represent a range of fields and expertise including international development, human rights, financial management, public relations, media and the arts.

The UK Executive Management team oversees all high level strategic decisions across Standing Voice's offices. The UK Programmes and Financial Management Team ensures that all implementation is delivered in line with organisational strategy and to the requirements of Standing Voice's funders, as well as internal and statutory financial regulations. Our UK Communications and Fundraising Team oversees the procurement of funding to sustain and grow our work, and ensure the charity maintains a high level of visibility around the world.

Our registered offices in Malawi and Tanzania are each governed by its own Board of Trustees which oversees all governance matters within the context of local standards, regulations and protocols. Standing Voice maintains a breadth of expertise on each of our local Boards which include human rights and employment lawyers, human rights advocates, management experts and representatives of National Human Rights Institutions. Staff team management in each of the Standing Voice country teams is handled by the Executive Director of the Malawi and Tanzania office respectively.

Harry Freeland is Executive Director of Standing Voice UK (since April 2014) and remains on the UK and Tanzania Board of Trustees. During the reporting period the charity had 6 paid staff members in the UK supported by a committed team of volunteers. Our global team comprises an additional 22 paid staff members based in Tanzania and 12 based in Malawi. Across all offices this equates to a total international staff team comprising 40 people.

People with albinism and their families are key decision-makers embedded at every level of Standing Voice. As trustees and senior leaders across our UK, Malawi and Tanzania offices, people with albinism and their families are actively engaged in governance, programme design and fundraising, building and shaping a culture of accountability grounded in, and responsive to, the lived experience of our service users.

## 2.5 Contributions of Volunteers

Standing Voice continues to work closely with skilled volunteers from a variety of professional and academic backgrounds who are committed to ending human rights abuses against people with albinism.

Our programmes are supported by a pool of local and international expert volunteer researchers, professors, ophthalmologists, dermatologists, geneticists and performance artists who continue to complement the development and expansion of our work through the provision of research, resource development, training, and ongoing mentorship during the reporting period.

Our volunteer engagement has resulted in a unique pool of expertise on albinism supporting Standing Voice's global operations. We have formalised this provision of expertise through the establishment of our advisory board, which plays a vital role in supporting our country Boards of Trustees and staff teams.

We are extremely grateful to all the volunteers who continued to inform and shape our life-saving programmes this year.

## 2.6 Our Purpose and Objectives

Standing Voice is an international NGO working in Tanzania and Malawi, with its headquarters in the United Kingdom. Standing Voice's primary objective is to improve the quality of life of people with albinism in Africa.

The objectives of the CIO are:

- I. the advancement of education;
- II. the advancement of mental and physical health and the saving of lives;
- III. the relief of poverty and the improvement of the conditions of life in socially and economically disadvantaged communities;
- IV. the promotion of human rights and the promotion of equality and diversity, in particular but without limitation so as to relieve the needs of people who are socially excluded by assisting them to integrate into society.

For the purposes of the above:

- I. "human rights" means human rights as defined in the Universal Declaration of Human Rights and subsequent United Nations conventions and declarations and will be promoted in particular by education about human rights and promoting respect for human rights;
- II. people who are "socially excluded" means people who are excluded from society, or parts of society, as a result of one or more of the following factors: financial hardship; youth or old age; ill health (physical or mental); disability or medical condition; discrimination on the grounds of sex, race, ethnic origin, religion, colour, creed or sexuality; poor education or skills attainment.

Standing Voice exists as a catalyst to amplify the voices of others. We aim to empower the people we work with to be the agents of change in their own lives, to build resilience and be healthy and self-sufficient. We currently focus on promoting the social inclusion of people with albinism in Tanzania and Malawi, whilst building the capacity of human rights defenders and partners in other countries in the region. Our team has over 18 years' experience working with this group and has pioneered innovative models of working that have a proven record of replication and scalability.

People with albinism are commonly the victims of social exclusion in Sub-Saharan Africa, which has led to witchcraft-fuelled murder and marginalisation from health and education services. Our work with this group centres around several programmatic areas: Skin Cancer Prevention, Low Vision and Education, Trauma Recovery, Economic Empowerment and Advocacy. Through our core programmes our support is holistic and comprehensive to reflect the complex needs of people with albinism in their local context. We achieve our objectives by collaborating with a network of local stakeholders (such as government bodies, local community groups and NGOs). All of our initiatives promote the social inclusion of people with albinism by:

- I. Advancing understanding and knowledge about albinism in wider society
- II. Advocating for progressive state action
- III. Developing the skills and expertise of both people with albinism and wider community members
- IV. Increasing the positive impact of local service providers
- V. Promoting the positive impact of local non-governmental stakeholders (civil society)

The trustees of Standing Voice declare that they have had regard to both the Charity Commission guidance on public benefit and section 17(5) of the Charities Act 2011 on public benefit in carrying out their duties to achieve the charity's objectives.

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### 3. PRINCIPAL ACTIVITIES

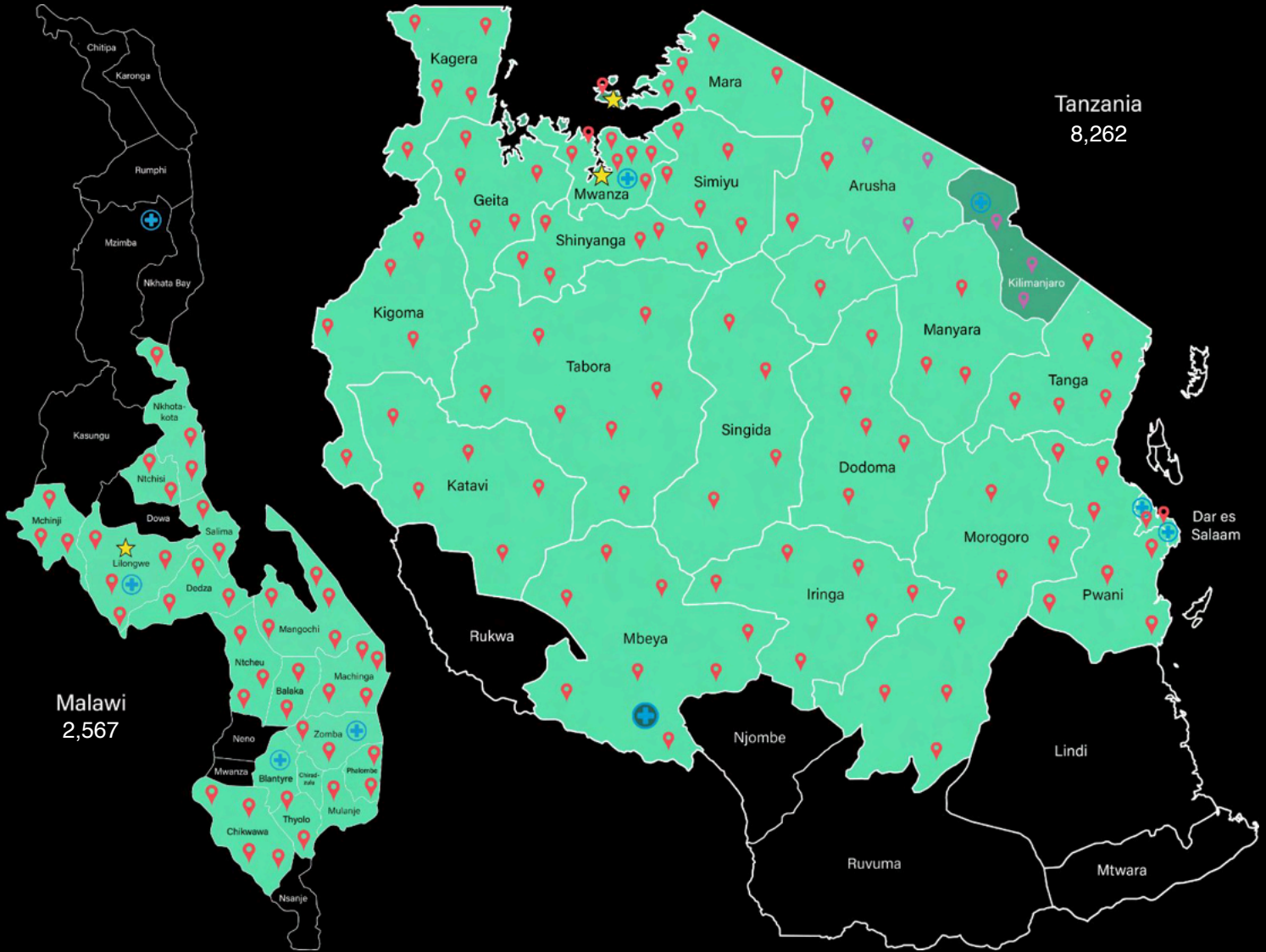
In 2023 we delivered programmes focused on improving access to Health, Education, Livelihoods, psychosocial support and Trauma recovery, reaching thousands of people with albinism across Tanzania and Malawi.

Through all these interventions we reached 10,829 people with albinism and thousands members of wider society through training and advocacy.










# Geographical reach (Dec 2023)

Total people with albinism served through all programmes: 10,829



## Current SCPP Operations

-  Skin Cancer Prevention Programme
-  RDTC DVO training region
-  Regions currently not served
-  Standing Voice Offices
-  Referral Hospitals
-  Clinics coordinated by Standing Voice
-  Clinics coordinated by the RDTC

### 3.2 Demographic Breakdown

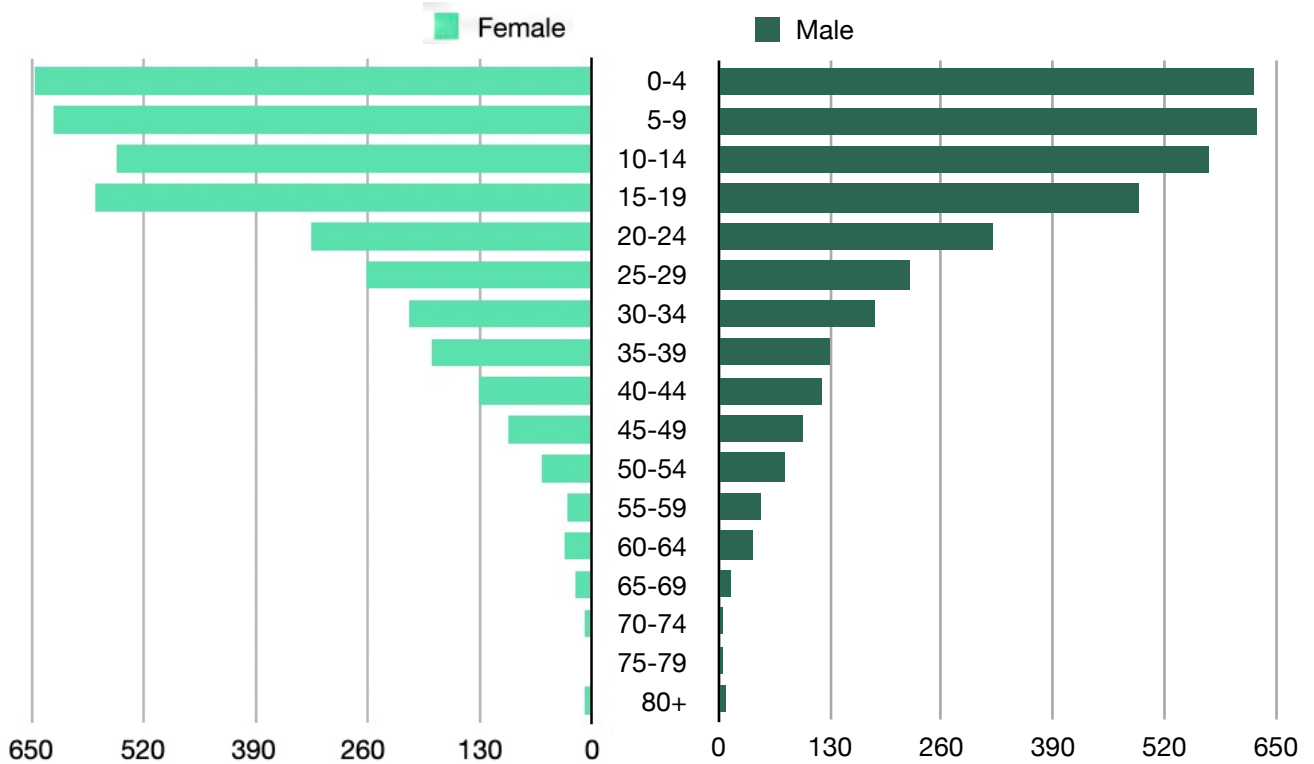
	Tanzania		Malawi	
	Number	%	Number	%
<b>Total registered patients (across all programs)</b>	8,262		2,567	
<b>Female</b>	4,213	51%	1,285	50.1%
<b>Male</b>	4,049	49%	1,282	49.9%
<b>Average age</b>	19		17	
<b>0-9</b>	2,652	32%	888	34.7%
<b>10-19</b>	2,729	33%	757	29.4%
<b>20-29</b>	1,220	14.8%	462	18.0%
<b>30-39</b>	773	9.4%	258	10.0%
<b>40-49</b>	494	6.0%	129	5.0%
<b>50-59</b>	236	2.9%	40	1.5%
<b>60-69</b>	120	1.5%	28	1.2%
<b>70 &gt;</b>	38	0.4%	5	0.2%

We are encouraged to see continued gender parity in our patient population, with women and men respectively comprising 51% and 49% of all registered patients in Tanzania, and 50.1% and 49.9% of all patients in Malawi. Younger age brackets continue to dominate our patient population in a manner that is consistent with the age distribution of the general population in both Tanzania and Malawi. In Tanzania, our average patient age is 19 and 65.1% of all registered patients are aged 19 or below; in Malawi, the average age is 17 and 64.0% of all registered patients are aged 19 or below. Across both countries 7,021 people (or 64.9%) of all registered patients are under the age of 19, and 80.4% are under the age of 30. Compared with 19.6% over 30, and just 4.3% over the age of 50.

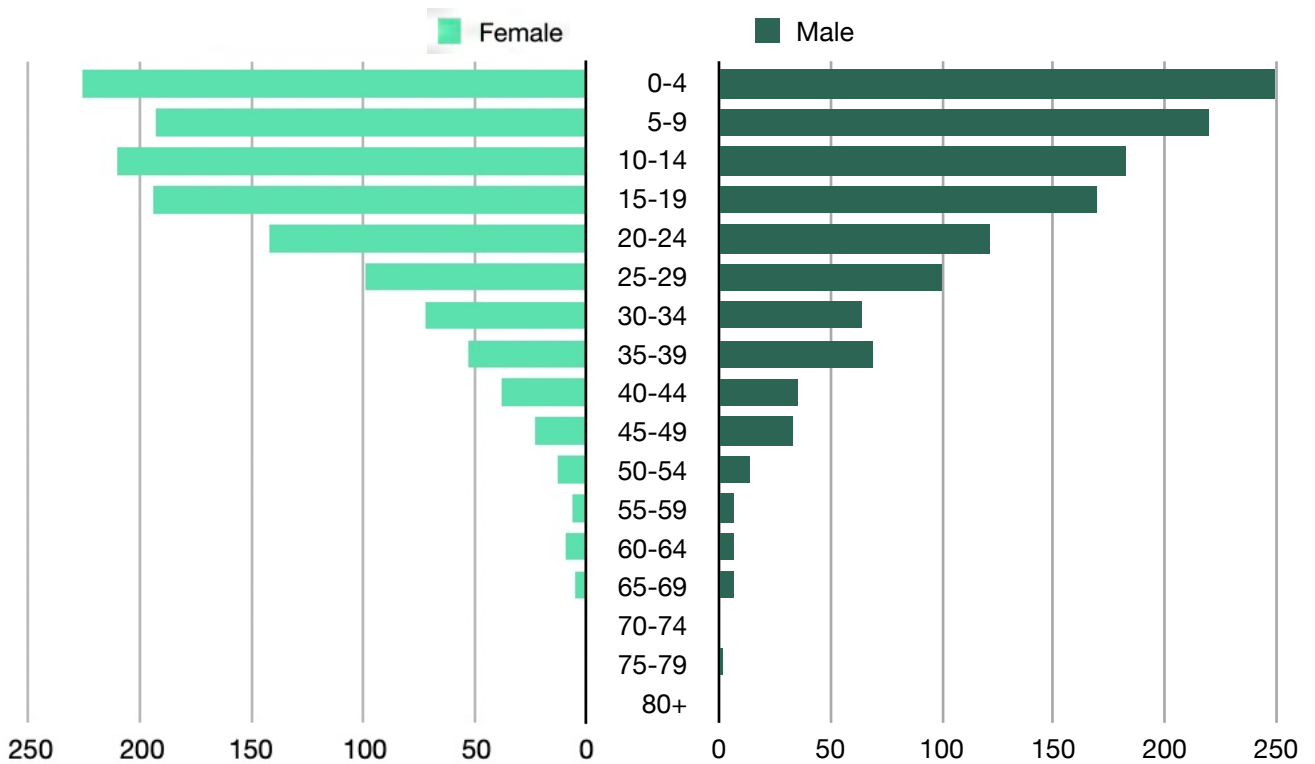


The population pyramids below demonstrate the distribution of our registered patient population. In Tanzania 65.1% of all registered clients are aged 19 or below, and in Malawi, 64.0% of all registered clients are aged 19 or below.

**Distribution of Registered Patients in Tanzania**



**Distribution of Registered Patients in Malawi**



## 4. SKIN CANCER PREVENTION PROGRAMME

### 4.1 Reach and Growth

To confront the skin cancer crisis faced by people with albinism in Africa, Standing Voice launched its Skin Cancer Prevention Programme (SCPP) in 2013. Today, this growing network of dermatology clinics is reaching 9,912 people with albinism (PWA) throughout Tanzania and Malawi. Declared best practice by the United Nations in 2017, this programme is delivered in partnership with the Governments of Tanzania and Malawi, and is supported by over 2000 health professionals and civil society actors. Through the support and close collaboration of the Foundation Pierre Fabre, European Commission and International league of Dermatology Societies in 2023 we have been able to expand the SCPP at scale, transforming it into the largest skin cancer prevention programme for people with albinism existing in Africa today.

Each clinic provides health education, skin examination, cryotherapy, and referral for surgery if required. Patients also receive sunglasses, locally made sun hats and a fresh supply of sunscreen at every clinic. Our objective is to support governments and civil society to build national programmes of skin cancer prevention that reach every region and serve the total population of people with albinism.

During 2023 we have expanded the SCPP into 2 new regions of Tanzania and 5 new districts of Malawi. We conducted mapping exercises and engagement meetings with govt and civil society to ensure the full mobilisation of PWA and their duty bearers in the delivery of the SCPP, and we have continued to deliver training to health professionals and community advocates, who lead the programme's expansion across both countries. We have seen significant growth in the number of patients enrolled across all programme areas, and we are on track for the SCPP to achieve national coverage of both Tanzania and Malawi by the end of 2027.

Indicator	Tanzania			Malawi		
	Target	Achieved	Difference	Target	Achieved	Difference
<b>Number of regions/districts covered by SCPP</b>	19	19	2	16	17	1
<b>Number of clinics delivered during reporting period</b>	228	237	9	106	144	38
<b>Total number of patients registered in the database</b>	5,130	7,345	2,215	1,920	2,567	642
<b>Patients seen in this period</b>	5,130	5,247	117	1,920	1,978	58
<b>New patients seen in this period</b>	540	1,075	535	114	761	642

By the end of 2023, the SCPP had exceeded or met all targets regarding patient reach and geographical coverage. The programme had registered 9,912 patients across Tanzania and Malawi, surpassing our combined target of 7,050 patients for both countries by a margin of 28.8%. This included 7,345 patients in Tanzania and 2,567 patients in Malawi.

19 regions of Tanzania were reached during this reporting period (meeting our target of 19 for the end of 2023), while 17 districts of Malawi were reached (surpassing our target of 16 districts). This means that today the SCPP is operational in 61.3% of all regions in Tanzania (19 of 31), and 60.7% coverage of all districts in Malawi (17 of 28). Clinics are now active in 206 Govt hospitals and health centres across both countries. 129 of these facilities are in Tanzania, and 77 are in Malawi. A total of 383 clinics were delivered across both countries during the reporting period. 237 of these were in Tanzania and 144 in Malawi. Since July 2021 and the start of the phase II partnership with the Foundation Pierre Fabre, 781 clinics have been delivered across Tanzania and Malawi.

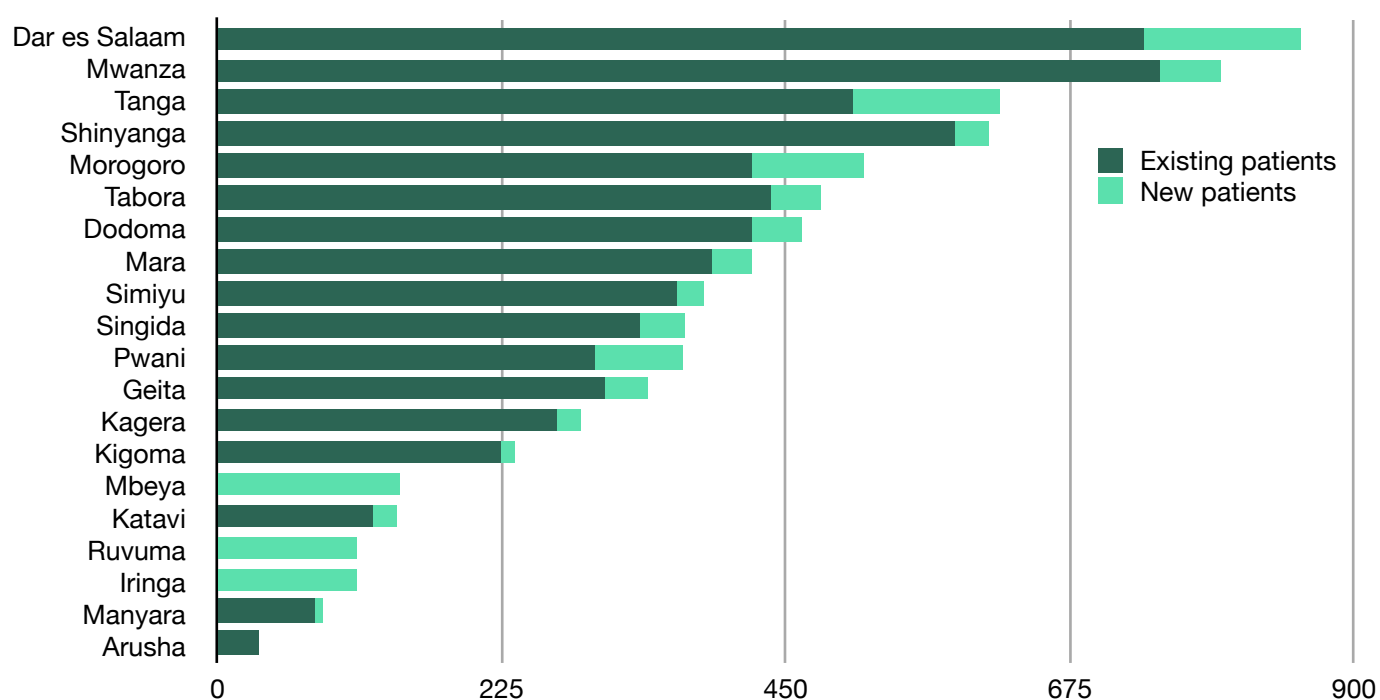
Across the entire year we welcomed a total of 1,836 new patients across both countries, reflecting a combined annual growth rate of 18.4%. This included 1,075 new patients registered in Tanzania (a growth rate of 14.6% from 2022). In Malawi, we saw 761 new patients in 2023 (a growth rate of 29.5% from 2022). The faster rate of patient growth in Malawi during 2023 was down to rapid expansion of the programme from 12 districts to 17.



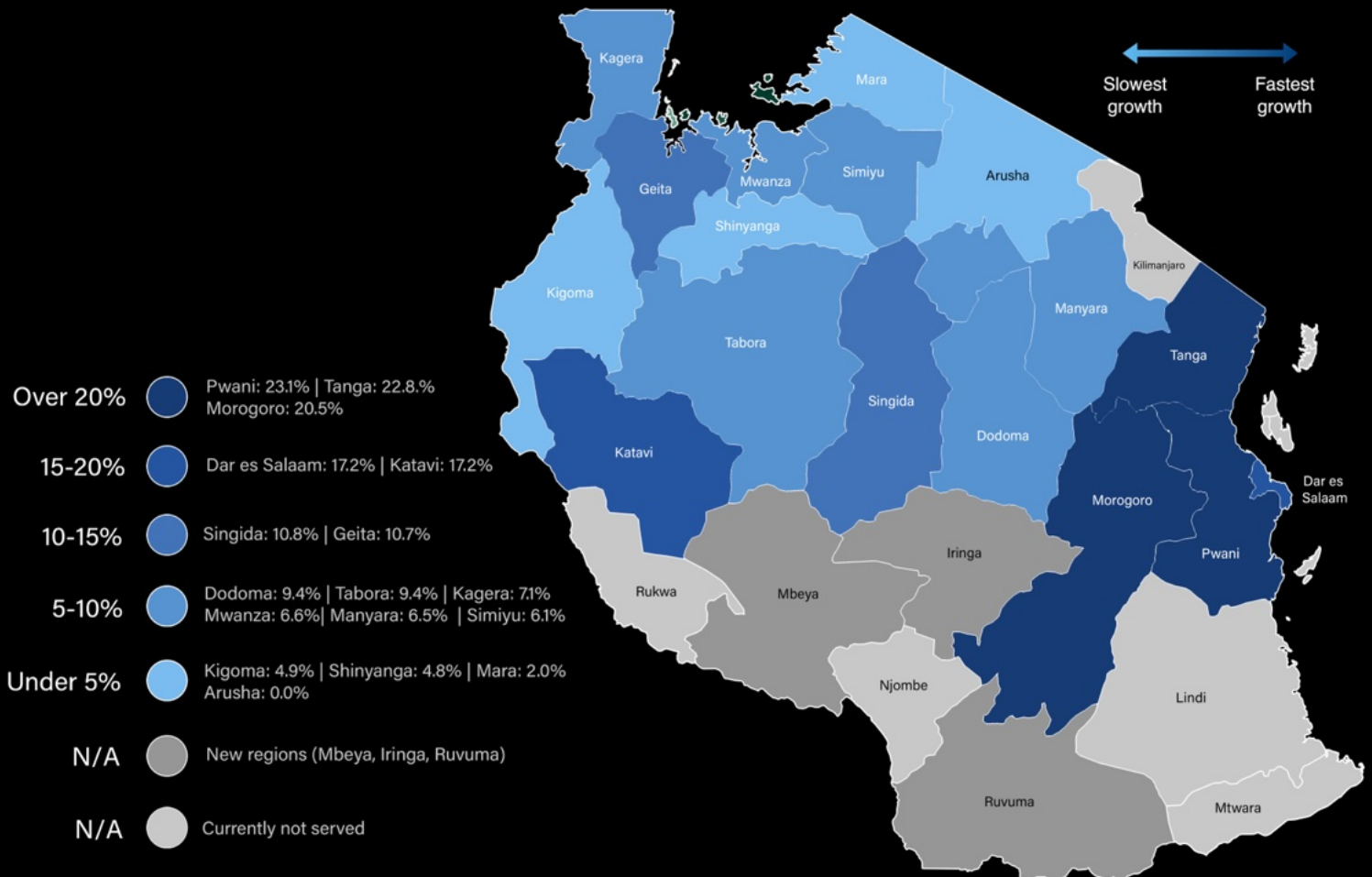
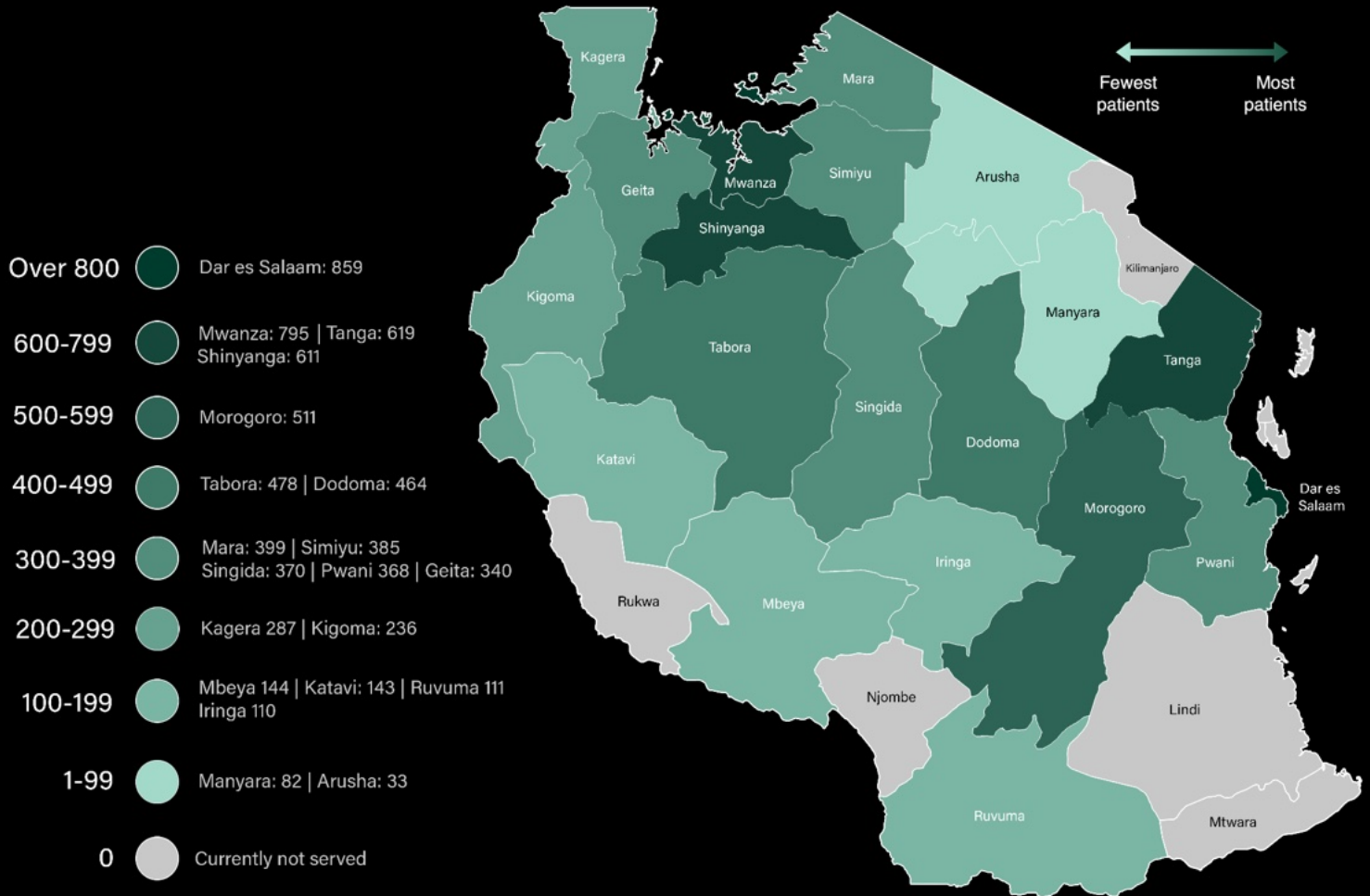
## 4.2 Geographic Breakdown SCPP

TANZANIA												
Registered Patients - Disaggregated by Region, Gender, and New/Existing												
Region	Existing patients			New patients						Total patients		
	M	F	Total	M	Growth in M (%)	F	Growth in F (%)	Total	Total Growth (%)	M	F	Total
Dodoma	229	195	424	16	7.0%	24	12.3%	40	9.4%	245	219	464
Katavi	46	76	122	13	28.3%	8	10.5%	21	17.2%	59	84	143
Tabora	206	231	437	21	10.2%	20	8.7%	41	9.4%	227	251	478
Geita	156	151	307	16	10.3%	17	11.3%	33	10.7%	172	168	340
Singida	134	200	334	16	11.9%	20	10.0%	36	10.8%	150	220	370
Mara	186	205	391	2	1.1%	6	2.9%	8	2.0%	188	211	399
Simiyu	202	161	363	14	6.9%	8	5.0%	22	6.1%	216	169	385
Kagera	136	132	268	9	6.6%	10	7.6%	19	7.1%	145	142	287
Kigoma	116	109	225	7	6.0%	4	3.7%	11	4.9%	123	113	236
Mwanza	352	394	746	24	6.8%	25	6.3%	49	6.6%	376	419	795
Shinyanga	321	262	583	18	5.6%	10	3.8%	28	4.8%	339	272	611
Dar es Salaam	350	383	733	56	16.0%	70	18.3%	126	17.2%	406	453	859
Tanga	236	268	504	52	22.0%	63	23.5%	115	22.8%	288	331	619
Arusha	12	21	33	0	N/A	0	N/A	0	0.0%	12	21	33
Manyara	40	37	77	2	5.0%	3	8.1%	5	6.5%	42	40	82
Morogoro	212	212	424	45	21.2%	42	19.8%	87	20.5%	257	254	511
Pwani	138	161	299	33	23.9%	36	22.4%	69	23.1%	171	197	368
Iringa	0	0	0	47	N/A	63	N/A	110	N/A	47	63	110
Mbeya	0	0	0	75	N/A	69	N/A	144	N/A	75	69	144
Ruvuma	0	0	0	42	N/A	69	N/A	111	N/A	42	69	111
<b>Total</b>	<b>3,072</b>	<b>3,198</b>	<b>6,270</b>	<b>508</b>	<b>16.5%</b>	<b>567</b>	<b>17.7%</b>	<b>1,075</b>	<b>17.1%</b>	<b>3,580</b>	<b>3,765</b>	<b>7,345</b>

Annually, we saw a 16.5% increase in registered male patients and a 17.7% increase in registered female patients in Tanzania. Our fastest-growing regions were Pwani (23.1%), Tanga (22.8%) and Morogoro (20.5%), while our slowest-growing regions were Mara (2.0%), Shinyanga (4.8%), Kigoma (4.9%), Simiyu (6.1%) Manyara (6.5%) and Mwanza (6.6%), which with the exception of Manyara are the regions where the SCPP has been operating longest.<sup>1</sup>

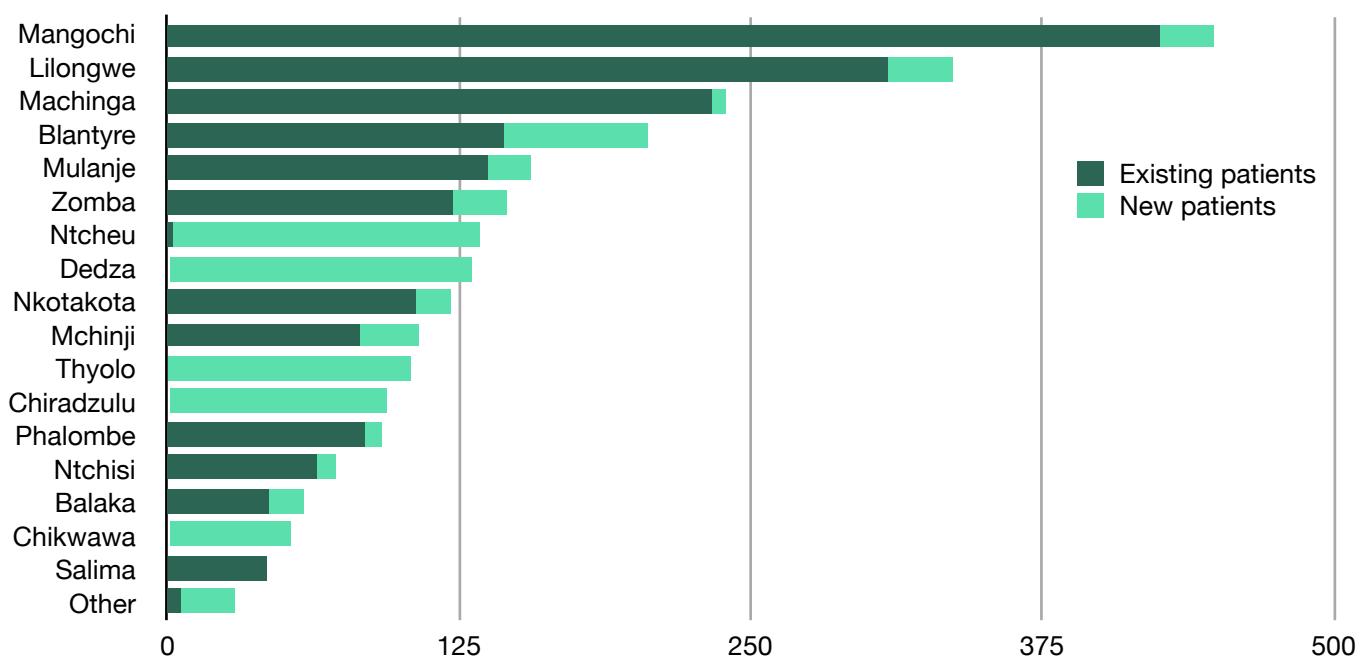


The top map indicates the distributional density of our registered patients in Tanzania: Dar es Salaam has the most patients (859) while Arusha has the fewest (33). The bottom map indicates regional growth rates in registered patients: Pwani is growing quickest (23.1%), while Mara is growing slowest (2.0%).



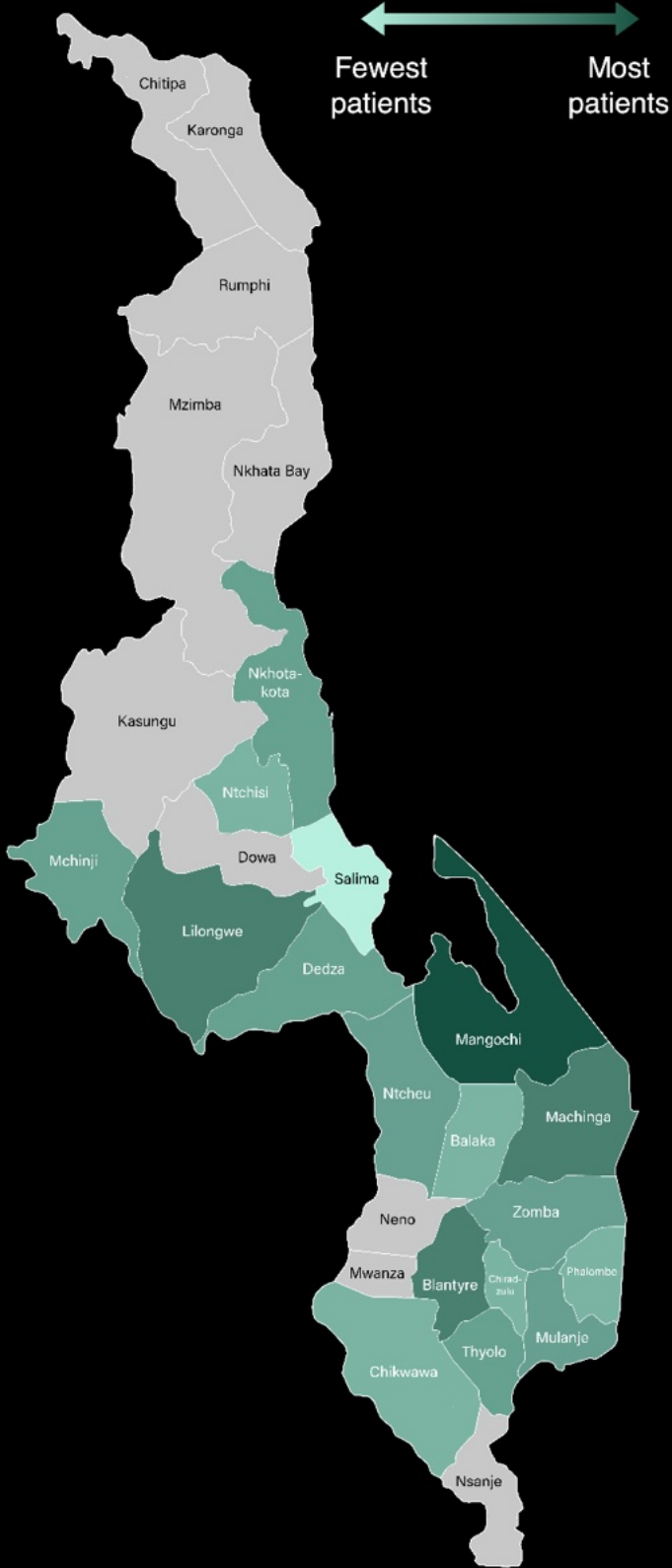
MALAWI Registered Patients - Disaggregated by Region, Gender, and New/Existing												
District	Existing patients			New patients						Total patients		
	M	F	Total	M	Growth in M (%)	F	Growth in F (%)	Total	Total Growth (%)	M	F	Total
Machinga	122	111	233	3	2.5%	3	2.7%	6	2.6%	125	114	239
Mangochi	186	240	426	11	5.9%	12	5.0%	23	5.4%	197	252	449
Zomba	63	59	122	14	22.2%	9	15.3%	23	18.9%	77	68	145
Phalombe	41	44	85	2	4.9%	5	11.4%	7	8.2%	43	49	92
Mulanje	68	69	137	8	11.8%	11	15.9%	19	13.9%	76	80	156
Balaka	23	21	44	8	34.8%	6	28.6%	14	31.8%	31	27	58
Dedza	1	0	1	68	N/A	61	N/A	129	N/A	69	61	130
Ntcheu	1	1	2	70	N/A	62	N/A	132	N/A	71	63	134
Blantyre	69	75	144	31	44.9%	31	41.3%	62	43.1%	100	106	206
Mchinji	49	33	82	10	20.4%	16	48.5%	26	31.7%	59	49	108
Lilongwe	153	156	309	12	7.8%	15	9.6%	27	8.7%	165	171	336
Chikwawa	1	0	1	24	N/A	27	N/A	51	N/A	25	27	52
Thyolo	0	0	0	51	N/A	53	N/A	104	N/A	51	53	104
Chiradzulu	1	0	1	47	N/A	45	N/A	92	N/A	48	45	93
Salima	27	16	43	0	0%	0	0%	0	0.0%	27	16	43
Nkotakota	52	54	106	12	23.1%	3	5.6%	15	14.2%	64	57	121
Ntchisi	34	30	64	5	14.7%	3	10.0%	8	12.5%	39	33	72
Other	5	1	6	10	N/A	13	N/A	23	N/A	15	14	29
<b>Total</b>	<b>896</b>	<b>910</b>	<b>1,806</b>	<b>386</b>	<b>42.6%</b>	<b>375</b>	<b>41.1%</b>	<b>761</b>	<b>41.9%</b>	<b>1,282</b>	<b>1,285</b>	<b>2,567</b>

Annually, we saw a 42.6% increase in registered male patients and a 41.1% increase in registered female patients in Malawi. By far our fastest-growing district was Balaka (31.8%), followed by Zomba (18.9%). Our longest running districts in Malawi; Mangochi (5.4%) and Machinga (2.6%) saw the slowest patient growth. Growth is N/A for Dedza and Ntcheu which have been entirely new in districts reach through this project.<sup>2</sup>

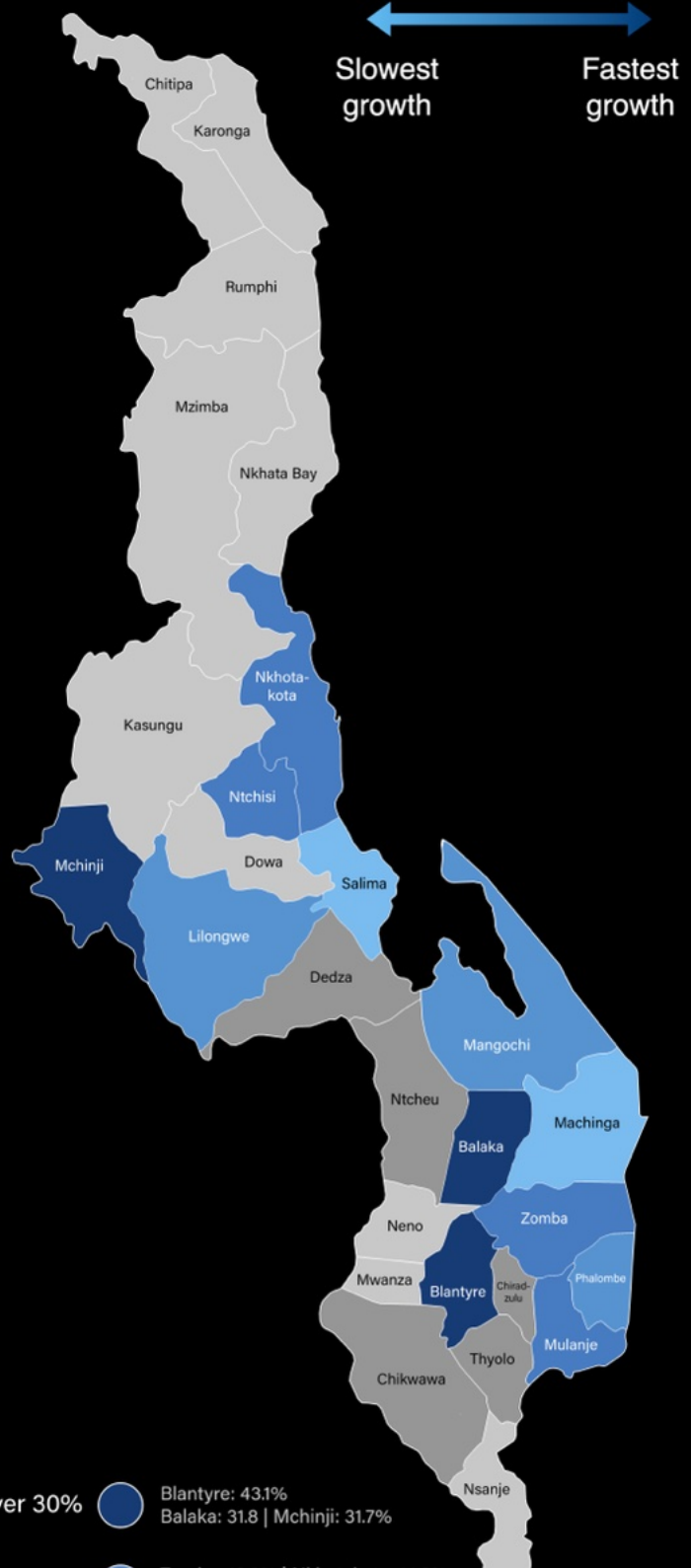


1. Page 9: Growth is N/A for Iringa, Mbeya and Ruvuma in Tanzania, which were entirely new regions in 2023.  
2. Page 10: Growth is N/A for Ntcheu, Dedza, Thyolo, Chiradzulu and Chikwawa, which were entirely new districts in 2023; and for 5 districts that we have 6 patients registered through delivery of International Albinism Awareness Day events. These additional districts combined as 'Other' in this table – are Mwanza, Nsanje, Nkhata Bay, Karonga and Dowa.

The map on the left indicates the distributional density of our registered patients in Malawi: Mangochi has the most patients (449) while Salima has the fewest (43). The map on the right indicates district growth rates in registered patients: the fastest growth was in Blantyre (43.1%), while Salima is growing slowest (0%).



- Over 400 ● Mangochi: 449
- 200-399 ● Lilongwe: 336 | Machinga: 239  
Blantyre: 206
- 100-199 ● Mulanje: 156 | Zomba: 145 | Ntcheu: 134 | Dedza: 130  
Nkhotakota: 121 | Mchinji: 108 | Thyolo: 104
- 50-99 ● Chiradzulu: 93 | Phalombe: 92 | Ntchisi: 72  
Balaka: 58 | Chikwawa: 52
- 1-49 ● Salima: 43
- 0 ● Currently not served



- Over 30% ● Blantyre: 43.1%  
Balaka: 31.8 | Mchinji: 31.7%
- 10-20% ● Zomba: 18.9% | Nkhotakota: 14.2%  
Mulanje: 13.9% | Ntchisi: 12.5%
- 5-10% ● Lilongwe: 8.7% | Phalombe: 8.2%  
Mangochi: 5.4%
- Under 5% ● Machinga: 2.6% | Salima: 0.0%
- N/A ● New regions (Dedza, Ntcheu, Chikwawa,  
Thyolo, Chiradzulu)
- 0 ● Currently not served

## 4.3 Retention

Indicator	Tanzania	Malawi	Total
Patients registered end of 2022	6,270	1,806	8,076
Patients registered end of 2023	7,345	2,562	9,907
Patients seen in 2023	5,247	1,978	7,225
New patients seen in 2023	1,075	756	1,831
Existing patients seen in 2023	4,172	1,222	5,394
Patients who did not return in 2023	2,098	584	2,682
Annual retention rate	66.5%	67.7%	66.8%

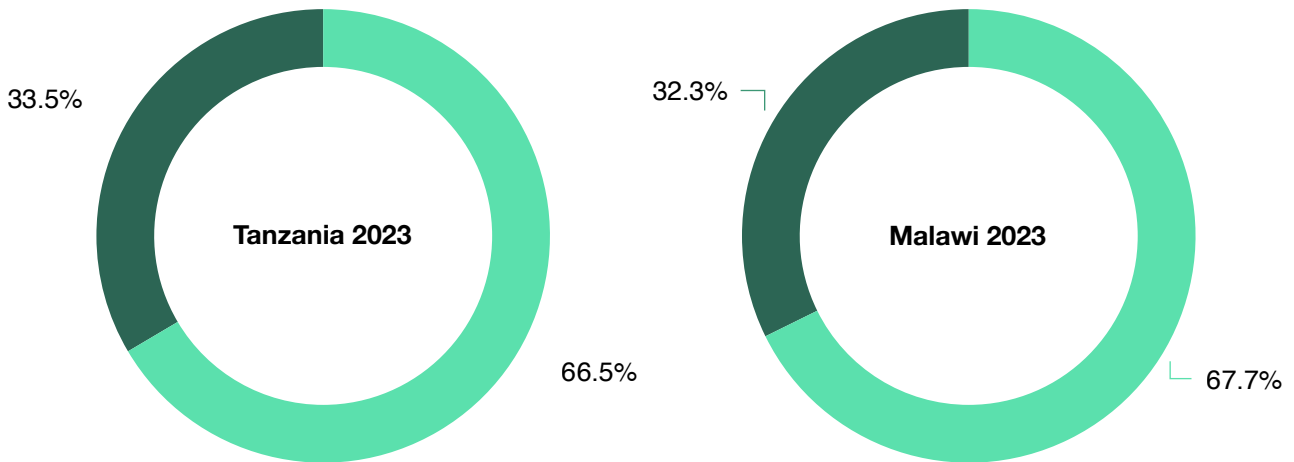
In Tanzania, we saw 5,247 individual patients throughout 2023. Of these, 4,172 patients were returning within 12 months (representing an annual retention rate of 66.5%). In Malawi the picture was similar: in 2023 we saw 1,978 patients, of whom 1,222 were returning within 12 months (an annual retention rate of 67.7%). Across both countries in 2023 we saw 7,225 individual patients, of whom 5,394 were returning within 12 months (a combined annual retention rate of 66.8%).

Patient retention is a crucial indicator that helps us to measure the success of the SCPP in mobilising people with albinism and promoting their access to regular healthcare in order to prevent skin cancer. Retention is complex and can be challenging to guarantee (and measure) for a number of reasons. Patient attendance can be undermined by a range of factors including:

- poverty and the cost or availability of transport
- employment commitments, especially for low-paid seasonal farmers
- childcare obligations
- Monsoons and poor weather conditions (increase in cyclones and flooding due to climate change making roads impassable)
- fear of consultation or treatment
- reluctance to attend hospital through fear of vaccination programmes such as during Covid-19
- patients already undergoing treatment
- patients not hearing about the service



● Patients returning within 12 months ● Patients not returning within 12 months



Although universal retention is virtually impossible, we work hard to maximise accessibility and retention by identifying and alleviating barriers to attendance where we can. Our electronic database helps us to monitor and analyse retention more accurately. This year we have been looking carefully at how retention varies by location, age and gender to identify those populations at greatest risk of dropping out, so we can invest additional resources in mobilisation among these groups. We ask specific questions in CommCare to help us understand the facilitators and obstacles that have an impact on the ability of patients to attend SCPP clinics.

During 2023 we scaled up the use of direct SMS communications with patients to announce upcoming clinic dates. This has not only strengthened and further diversified the methods we use to mobilise patients to clinics, but it also allows for easier follow up with patients if they are demonstrating usual patterns of attendance, or if they're high risk and require more careful tracking and follow up. For example we are able to identify patients who have not returned to clinics in 12 months or longer, and contact these individuals directly to understand the reasons for this dropout and encourage future attendance.



To ensure high patient turnout we deploy a diverse range of methods to help mobilise people with albinism and their families to clinic sites. Methods of mobilisation include coordination lead by Albinism Associations, Govt Social Welfare departments and school teachers, radio announcements, social media communications and direct SMS messages to patients phones.

To track and evaluate mobilisation clients are asked a series of questions on how they heard about the service. The table below demonstrates analysis of the most effective forms of mobilisation during 2023.

How did you hear about the clinic?	Tanzania 2023		Malawi 2023		Total	
<b>Number of people</b>	8 345		3 232		11 577	
<b>MSN message</b>	1,695	20.3%	172	5.3%	1,867	16.1%
<b>Albinism Associations</b>	4,301	51.5%	2,015	62.4%	6,316	54.7%
<b>Social Welfare Officers / Health Surveillance Assistants</b>	1,482	17.8%	641	19.8%	2,123	18.3%
<b>Teacher / School</b>	608	7.3%	253	7.8%	861	7.4%
<b>Relative / Neighbour</b>	61	0.7%	48	1.5%	109	0.9%
<b>Radio advert</b>	21	0.3%	18	0.6%	39	0.3%
<b>Social Media</b>	107	1.3%	38	1.2%	145	1.3%
<b>Other</b>	70	0.8%	47	1.4%	117	1.0%

From the table above we see a similar pattern of success from the different types of mobilisation methods deployed across both countries. The most common way patients reported hearing about clinics was via their albinism associations leaders, which equated to 51.5% of all PWA mobilised in Tanzania and 62.4% in Malawi. The role of Social Welfare Officers and Health Surveillance Assistants played a significant role in mobilising patients to clinics with 17.8% of all patients in Tanzania and 19.8% in Malawi hearing about clinics through these Govt actors. Meanwhile, the education system in both countries continued to play a key role in PWA accessing dermatology services with 7.3% of PWA in Tanzania and 7.8% of PWA in Malawi hearing about clinics through teachers and schools. At the end of 2022 Standing Voice introduced direct MSN messaging to patients phones in Tanzania which had an immediate impact in 2023, with 20.3% of all PWA in Tanzania and 5.3% in Malawi hearing about clinics via MSN messaging. The lower figure in Malawi is a result of this new method of mobilisation being deployed later on in 2023.

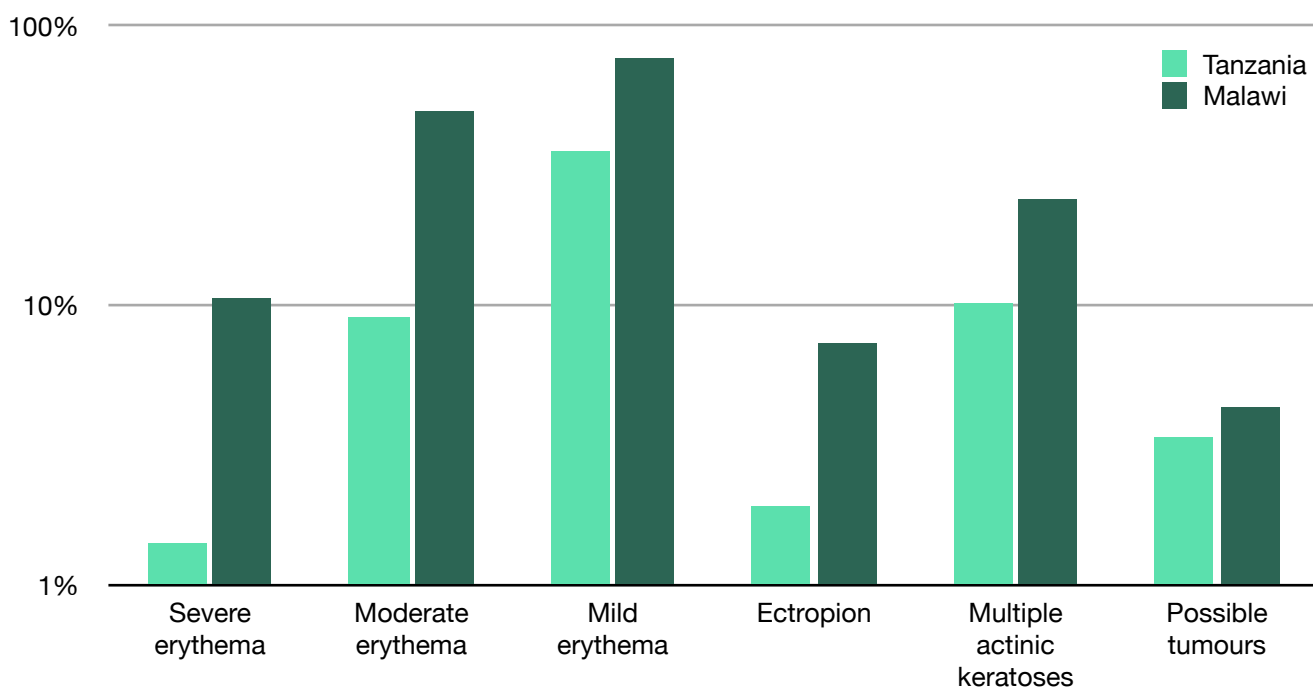


## 4.4 Screening and Medical Management

Indicator	Tanzania		Malawi		Total	
<b>Total patients seen</b>	5,247		1,978		7,225	
<b>Number of examinations</b>	8,345		3,232		11,577	
<b>Number of cryotherapy procedures<sup>7</sup></b>	3,047	36.5%	2,586	81.1%	5,633	48.7%
<b>Number of patients receiving cryotherapy</b>	1,159	22.0%	920	46.5%	2,079	28.8%
<b>Number patients referred for surgical procedures</b>	306	5.8%	169	8.5%	475	6.6%
<b>Number of examinations where patients present with...</b>						
Severe erythema	113	1.4%	345	10.7%	458	4.0%
Moderate erythema	750	9.0%	1,580	48.9%	2,330	20.1%
Mild erythema	2,966	35.5%	2,490	77.0%	5,456	47.1%
Ectropion	157	1.9%	237	7.3%	394	3.4%
Multiple AKs	840	10.1%	770	23.8%	1,610	13.9%
Possible tumours	286	3.4%	140	4.3%	426	3.7%

Clinical data from this reporting period reveals a higher prevalence of skin conditions among patients in Malawi than in Tanzania. As a proportion of the total number of examinations delivered in each country, Malawi scored much higher in cryotherapy use 81.1%, compared to 36.5% in Tanzania. In addition multiple Actinic keratosis were found during 23.8% of all examinations conducted in Malawi, compared with 10.1% in Tanzania. Rates of erythema (sunburn) were three times more prevalent in Malawi than Tanzania across each of our three indicators used to record the severity of erythema on each patient; severe, moderate and mild. This is a trend we'd expect to see with the comparatively longer history of the SCPP in Tanzania, which has led to a greater baseline awareness and understanding of skin cancer and preventative measures among people with albinism. Due to continued rapid expansion of the SCPP in Malawi during 2023 we enrolled a large number of new patients who had never before accessed Dermatology services. This provides additional reasons for the higher rates of skin conditions observed in the country during the reporting period.

**Prevalence of Clinical Conditions among Patients Seen (January – December 2023)**

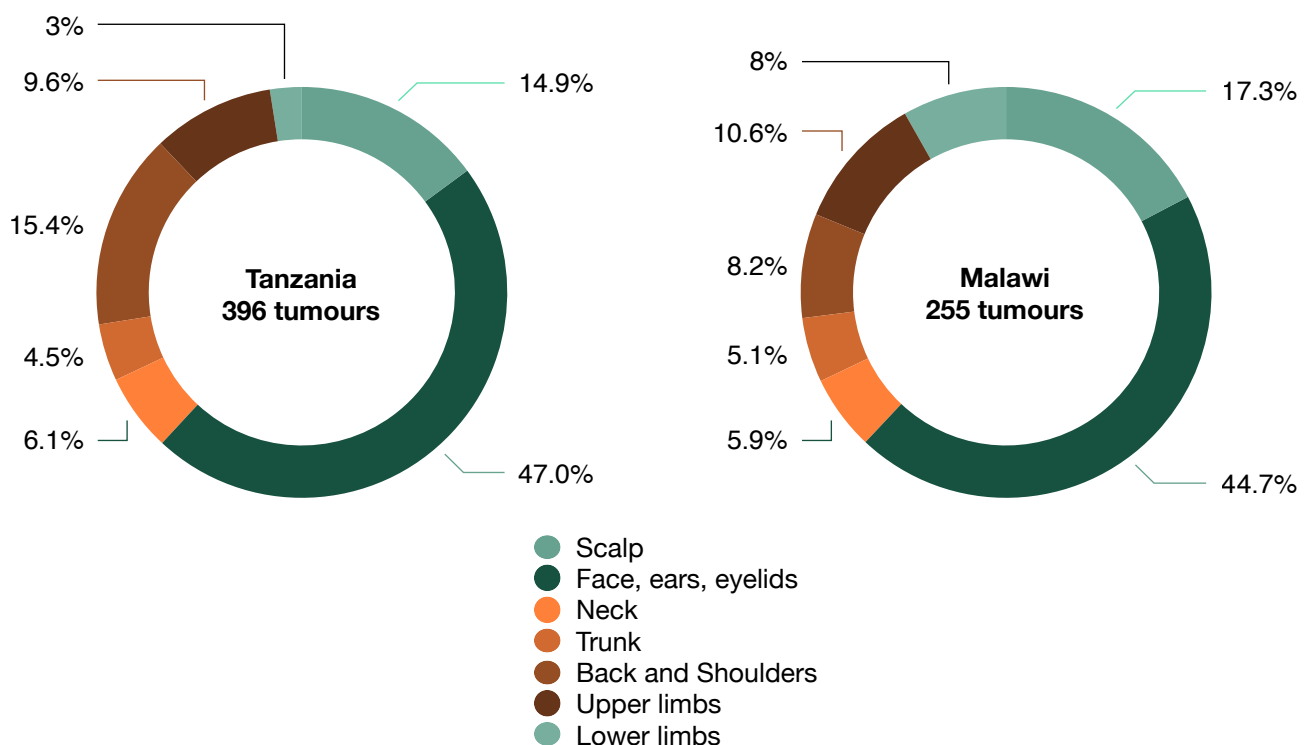


Provisional doctor's diagnosis during clinics 2023				
Indicator	Tanzania		Malawi	
<b>Possible tumours identified during clinics</b>	<b>396</b>		<b>255</b>	
SCC	176	44.4%	156	61.2%
BCC	181	45.7%	52	20.4%
Other/unknown	39	9.8%	47	18.4%
<b>Distribution of possible tumours by body part</b>	<b>396</b>		<b>255</b>	
Scalp	59	14.9%	44	17.3%
Face, ears, eyelids	186	47.0%	114	44.7%
Neck	24	6.1%	15	5.9%
Trunk	18	4.5%	13	5.1%
Back and shoulders	61	15.4%	21	8.2%
Upper limbs	38	9.6%	27	10.6%
Lower limbs	10	2.5%	21	8.2%

A total of 651 possible tumours were provisionally diagnosed during SPPP clinics. In Tanzania, doctors identified 396 possible tumours in 306 patients. 44.4% of tumours were identified as SCCs (down from 49.6% in 2022), 45.7% as BCCs (up from 41.9% in 2022), and 9.8% as other or unknown conditions (up from 8.5% in 2022). In Malawi, doctors found 255 possible tumours in 169 patients, with 61.2% diagnosed as SCC (up from 59.9% in 2022), 20.4% as BCC (down from 26.2% in 2022), and 18.4% as other or unknown (up from 13.9% in 2022).

Distribution of tumours identified on body parts was similar in both countries. The body parts most affected in both Tanzania and Malawi was the face, ears and eyelids, with 61.9% and 62.0% of all tumours identified being found on these three areas of the body.

**Distribution of tumours by body parts in 2023**



## 4.5 Referral Management

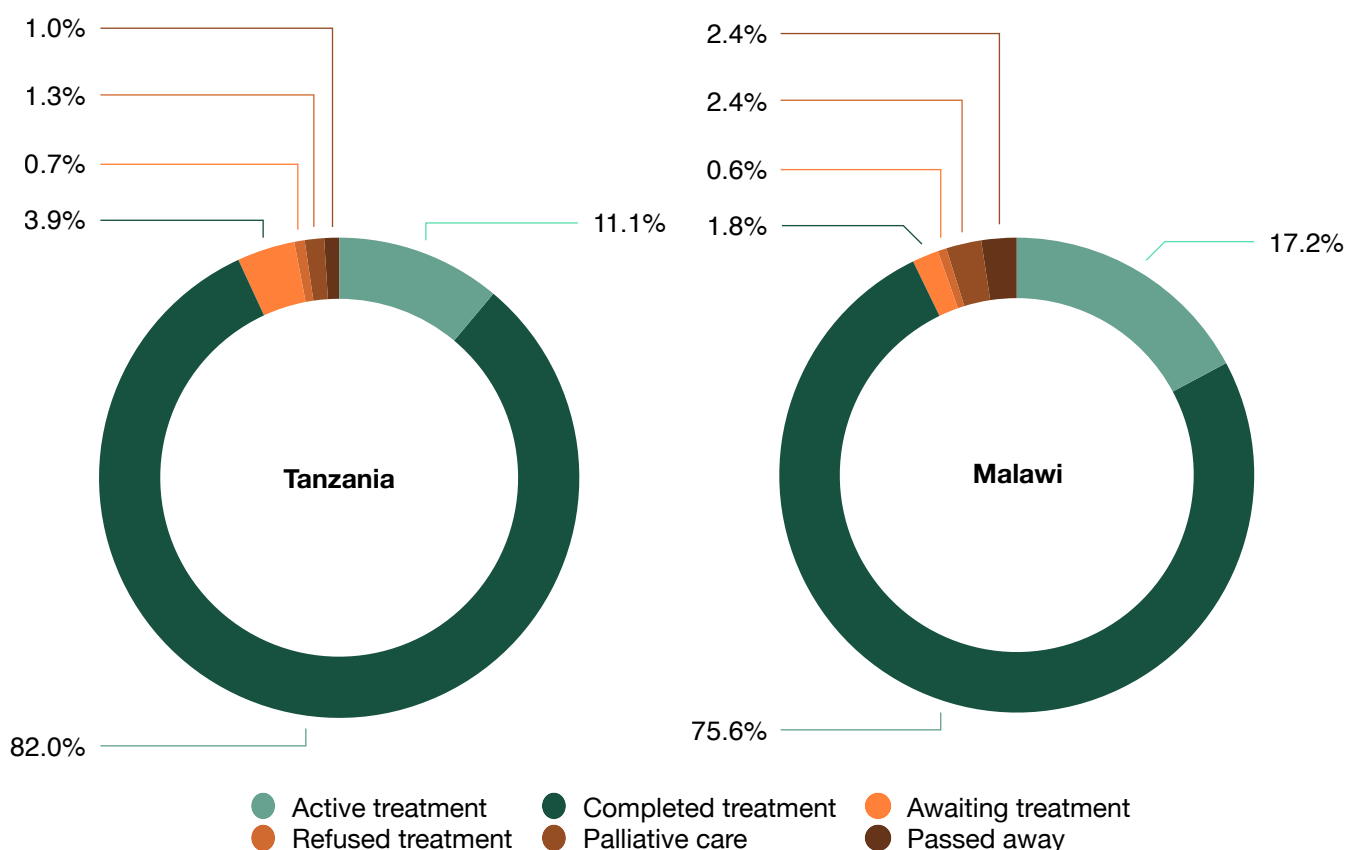
From January to December 2023, 475 patients were referred for further treatment by dermatologists at SCPP clinics. This included 306 patients in Tanzania and 169 patients in Malawi.

Patient Referral Status 2023							
Indicator	Tanzania		Malawi		Total		
<b>Total number of patients sent for referral</b>	<b>306</b>		<b>169</b>		<b>475</b>		
<b>Completed treatment</b>	251	82.0%	128	75.6%	379	79.8%	
<b>Active treatment</b>	34	11.1%	29	17.2%	63	13.3%	
<b>Awaiting treatment</b>	12	3.9%	3	1.8%	15	3.2%	
<b>Refused treatment</b>	2	0.7%	1	0.6%	3	0.6%	
<b>Undergoing palliative care</b>	4	1.3%	4	2.4%	8	1.7%	
<b>Passed away</b>	3	1.0%	4	2.4%	7	1.5%	

This year there were 306 referrals made in Tanzania and 169 in Malawi. Encouragingly, the majority of referred patients have now completed their treatment (82.0% in Tanzania and 75.6% in Malawi). Some patients are still in active treatment (11.1% in Tanzania and 17.2% in Malawi), while 3.9% and 1.8% of patients respectively are awaiting treatment.

A small minority of patients have refused treatment due to a number factors. Patients sometimes refuse treatment in fear of surgery, or because of financial or logistical obstacles involved in leaving their homes, jobs or families and travelling to receive treatment.

**Patient referral status 2023**



Referral Results 2023						
Indicator	Tanzania		Malawi		Total	
<b>Patients for whom histology results are available</b>	273		138		401	
<b>Confirmed diagnoses<sup>5</sup></b>	<b>316</b>		<b>149</b>		<b>465</b>	
<b>SCC</b>	156	49.4%	57	38.3%	213	45.8%
<b>BCC</b>	139	44.0%	76	51.0%	215	46.2%
<b>Other e.g. ulcers, benign lesions, warts, cysts etc.</b>	21	6.6%	16	10.7%	37	8.0%

During 2023 we received the histology results of 316 biopsies in Tanzania and 149 biopsies in Malawi. In Tanzania, 49.4% of results were confirmed as SCCs, 44% as BCCs, and 6.6% were other conditions, benign or non-cancerous. In Malawi, 38.3% of results were confirmed as SCC, 51.0% as BCC, and 10.7% were other conditions.

In new locations the SCPP continues to see patients with advanced tumours. At the end of 2023 4 patients in Tanzania and 4 patients in Malawi were receiving palliative care support. Sadly 7 patients passed away from skin cancer during the reporting period (3 in Tanzania and 4 in Malawi).

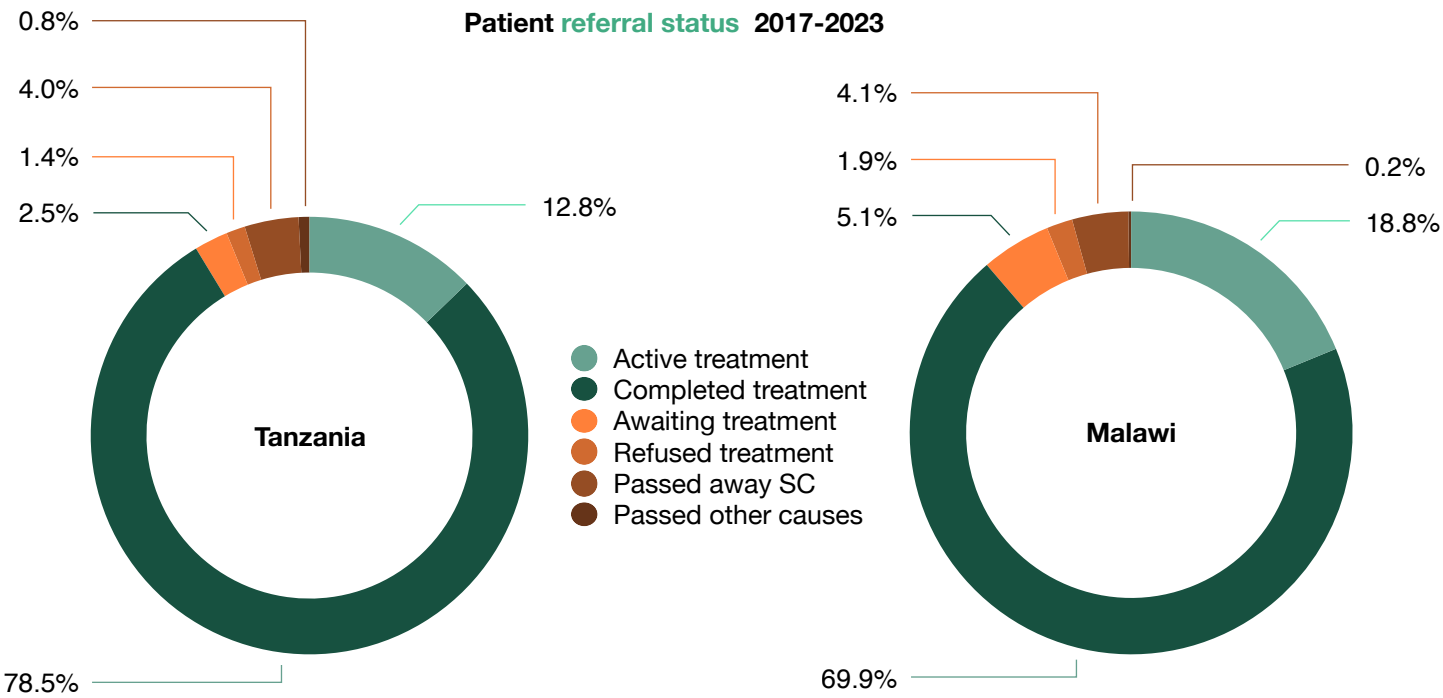
5. Patients often present with multiple lesions and as a result will have multiple biopsies taken. This is why the number of confirmed diagnoses is greater than the number patients with histology results available



*"I have had skin cancer several times and Standing Voice has facilitated treatment at a regional hospital. I cannot imagine where I would be without access to these clinics. In my village people did not know what albinism was and, I myself, did not know what causes albinism. Thanks to health [education] sessions [conducted] at clinics, I have learned a lot more about my condition. I am now able to educate others on albinism and I have become more confident in myself".*  
**Barnabas Magashi Shilinde, Biharamulo, Kagera district, Tanzania**

Total patient referrals and status since 2017						
Indicator	Tanzania		Malawi		Total	
Total number of patients referred for surgery	1,065		468		1,533	
Completed treatment	838	78.7%	327	69.9%	1,165	76.0%
Active treatment	136	12.8%	88	18.8%	224	14.7%
Waiting for treatment	27	2.5%	24	5.1%	51	3.2%
Refused treatment	14	1.2%	9	1.9%	23	1.5%
Passed away from skin cancer	41	4.0%	19	4.1%	60	3.9%
Passed away from other causes	9	0.8%	1	0.2%	10	0.7%

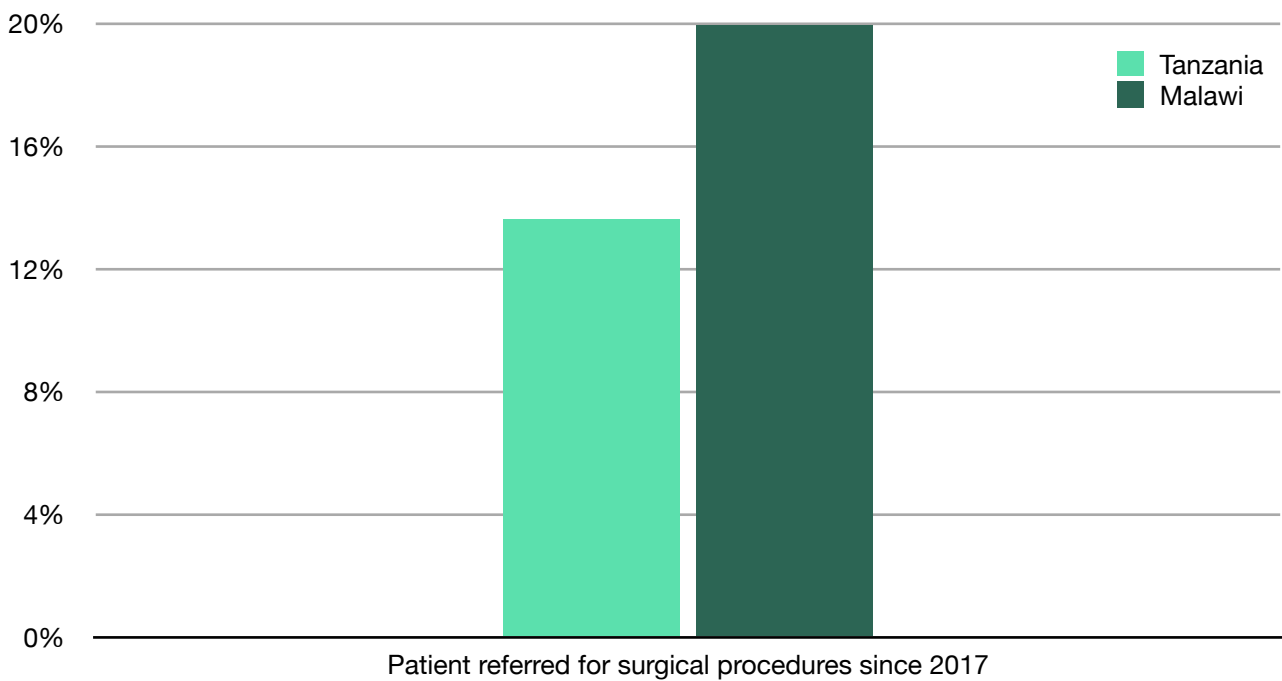
Across Tanzania and Malawi there has been a total of 1,533 referrals made through the SCPP since 2017. 1,065 of these have been made in Tanzania and 468 in Malawi. The vast majority of patients referred for skin cancer treatment since 2017 have completed their treatment (78.7% in Tanzania and 69.9% in Malawi). Some patients continue to undergo active treatment (12.8% in Tanzania and 18.8% in Malawi), which includes 6 patients in Tanzania and 13 patients in Malawi who are currently receiving palliative care treatment. 60 patients registered in the SCPP have passed from from skin cancer since 2017.<sup>6</sup>



*"Thanks to Standing Voice, I was able to have a wound [skin cancer] on my face removed. After this experience I now regularly return to [clinics] get my skin checked, and the [clinical] team have become like a family to me. At clinics, patients are treated well and we are able to learn more about our condition [albinism] and receive healthcare. I can now get free sunscreen and sun hats when I need it to protect my skin".*

**Rose Temaheri Joseph, Tabora, Tanzania**

## Percentage of all registered patients referred for skin cancer surgery since 2017



13.6% of all registered patients in Tanzania and 19.8% of all registered patients in Malawi have been referred for surgery or other treatments since 2017. These are high percentages that demonstrate the scale of the skin cancer crises facing people with albinism in Africa, particularly in Malawi where the programme has been operating for a shorter timeframe.

*"The Skin Cancer Prevention Programme has saved my life and I now have hopes to see my children grow."*  
**Skin Cancer patient**

## 4.6 Sun Protection Measures

Indicator	Tanzania			Malawi			Total all years
	S2 2021	2022	2023	S2 2021	2022	2023	
Number of jars of sunscreen distributed	8,894	14,816	22,093	1,722	12,300	9,731	69,556
Number of individuals receiving sunscreen	3,269	4,651	5,247	661	1,521	1,978	17,327
Number of sunglasses distributed	0	3,795	5,214	15	269	177	9,470
Number of hats produced locally	4,381	7,458	13,350	N/A	N/A	N/A	25,183
Number of hats distributed	3,269	7,290	8,345	238	1,431	2,620	23,193
Number of umbrellas distributed	192	505	692	0	29	20	1,438
UV protective lip balm	0	0	0	0	567	876	1,443

During 2023 the SCPP distributed thousands of sun-protective items across Tanzania and Malawi. In Tanzania this included 22,093 pots of sunscreen, 8,345 wide-brimmed hats, 692 umbrellas and 5,214 sunglasses. In Malawi this included 9,731 pots of sunscreen, 2,620 wide brimmed hats, 20 umbrellas, 177 sunglasses, and 876 UV protective lip balms.

Since the start of the phase II SCPP project in July 2021, a combined total of 122,427 sun protective items have been distributed to persons with albinism across Tanzania and Malawi. This includes 25,183 wide brimmed hats which were manufactured locally by tailors with albinism at the Standing Voice Umoja Training Centre in Tanzania, and distributed free through the SCPP clinical network. During 2023 we scaled up production and exportation of hats to Malawi.

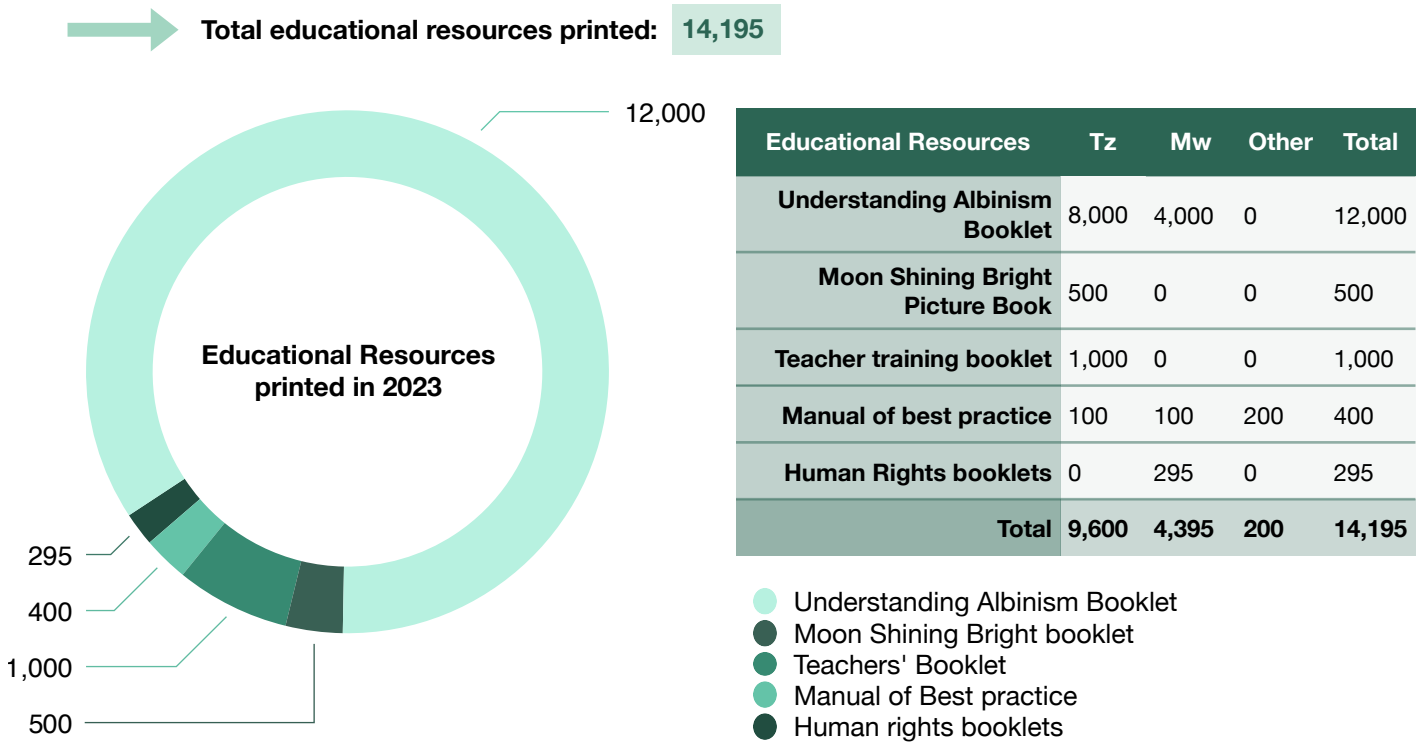


*Photo: A girl wears a locally made sun hat distributed to people with albinism through the skin cancer prevention programme in Tanzania and Malawi*

## 4.7 Educational resources

The SCPP provides an important avenue for the dissemination of specialist educational resources. Standing Voice has developed a wide range of booklets, films, and pop-up theatre performances to train and educate patients, communities and service providers. During 2023 we printed 14,195 education resources in the form of brochures, booklets and manuals which were distributed across all programme areas to people with albinism, their families and service providers. 9,600 of these were for distribution in Tanzania and 4,395 in Malawi. Whilst 200 were for distribution in other African countries.

To support capacity strengthening for health professionals, we continued to distribute and utilise the ‘*manual of best practice in dermatological care for patients with albinism*’ to support training and improve service delivery.



During 2023 resources were disseminated through dermatology and vision clinics, counselling sessions, training events, and directly in schools. They included:

- An information booklet for people with albinism called ‘*Advice and Support for People With Albinism, Families and Caregivers*’ available in Swahili and Chichewa
- A children’s story and picture book (written by Dutch illustration duo Happy Made By) called *Moon, Shining Bright!*, which centres around the life of a fictional young girl with albinism called Moon
- A teacher training booklet ‘*Albinism: An Information Booklet for Teachers*’ available in three languages
- The Manual of Best Practice for skin cancer management of PWA, available in French and English
- A human rights booklet, ‘*Guidance for community Advocates: human rights of persons with albinism*’, targeting PWA, families and albinism advocates - available in Chichewa and English

Throughout 2023 we screened a range of educational films about albinism and human rights during advocacy events and in waiting areas at vision clinics. These films included an animated adaptation of children’s story book called *Moon, Shining Bright!*, developed by Inside the Same – as well as [Jikubali](#), a documentary funded by the Swedish Institute Creative Force and co-produced by Standing Voice, the Tanzania Albinism Society, and Imagine What We Can Do - we also screened [Surviving the Sun](#), a short documentary charting the Skin Cancer Prevention Programme co produced by Standing Voice and the Fondation Pierre Fabre.

By sensitising patients and their duty bearers to understand and address the challenges arising from life with albinism in Tanzania and Malawi, these written and visual resources are playing a critical role in enabling thousands of people with albinism to take charge of their health and claim their rights.



Standing Voice ni shirika lisilo la kiserikali linalotetea haki za watu wenye ualbino nchini Tanzania

P.O. Box 1902, Isamilo, Mwanza, Tanzania

Namba maalum ya simu 0800 750318  
Tovuti [www.standingvoice.org](http://www.standingvoice.org)  
Barua pepe [info@standingvoice.org](mailto:info@standingvoice.org)  
Facebook [@standingvoicetanzania](https://www.facebook.com/standingvoicetanzania)  
Instagram [@standingvoicetz](https://www.instagram.com/standingvoicetz)  
Twitter [@standingvoice](https://twitter.com/standingvoice)

Ninaweza kupata wapi habari zaidi kuhusu ualbino?

TANZANIA ALBINISM SOCIETY (TAS)  
P.O. Box 9644, Dar es Salaam, Tanzania  
Simu +255 22 2110527  
Tovuti [www.tas.or.tz](http://www.tas.or.tz)  
Info [info@tas.or.tz](mailto:info@tas.or.tz)



FONDATION PIERRE FABRE  
Recognized as being of public utility

Ushauri Na Msaada Kwa Watu Wenye Ualbino, Familia Na Walezi



*"I have been attending clinics [the SCPP] for the past 8 years. When I compare my health back then, to how it is now, it's easy to see how my life has changed. These clinics are lifesaving. I now feel safe knowing that I can access skin check ups and protection items such as sunscreen and hats regularly. These years have been so important to me and I am so thankful".*

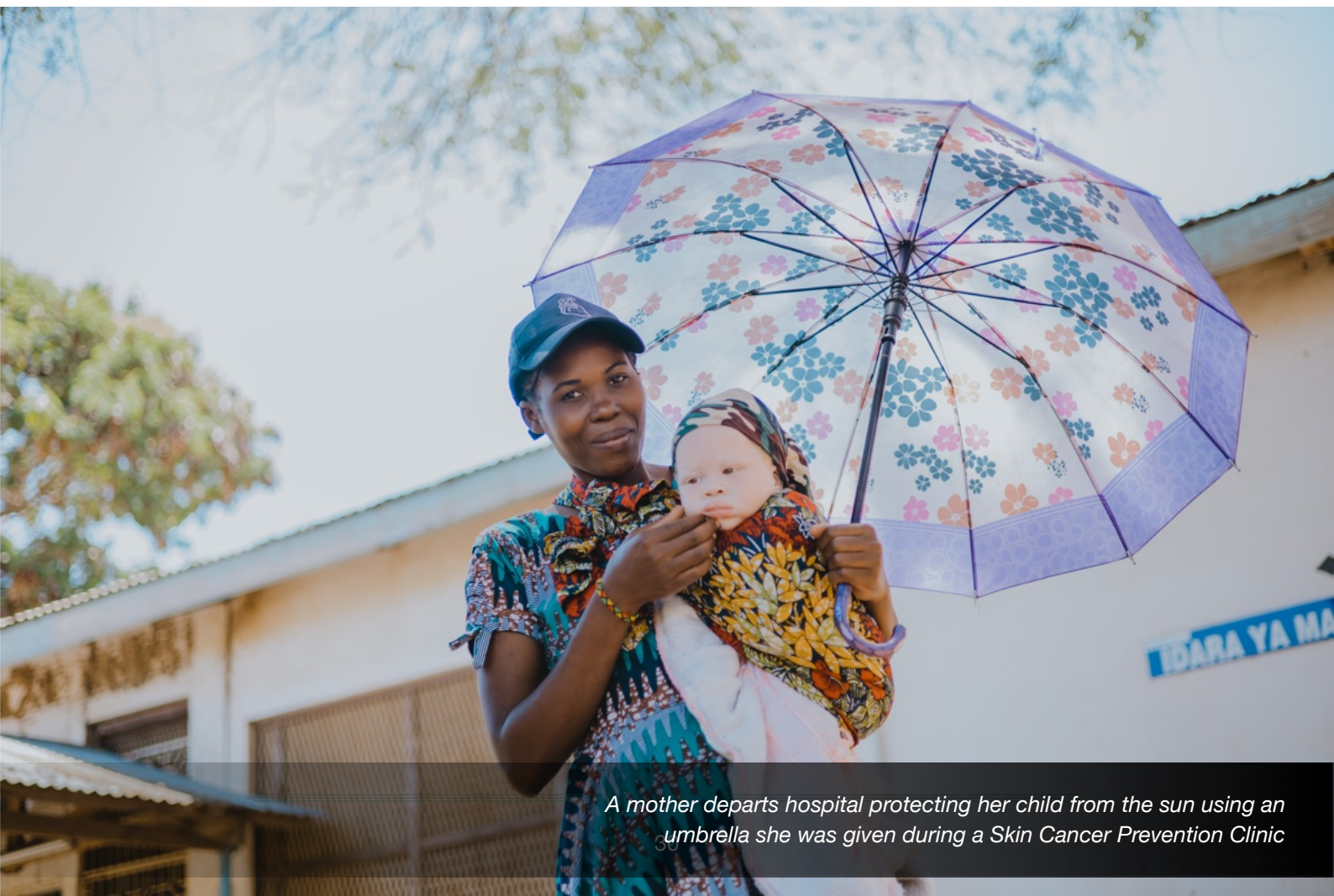
**Siyajali Magenge, Kigoma, Tanzania**

## 4.8 Community Knowledge

	Indicator	Tanzania	Malawi	Total
	<b>Number of awareness sessions</b>	394	243	637
	<b>Number of patients and their relatives present at awareness sessions</b>	12,557	4,733	17,290
	<b>Number of communication tool(s) used for the general public</b>	4	5	9
	<b>Number of communication tool(s) distributed in the form of a brochure</b>	10,249	2,507	12,756
	<b>Number of community advocate training events</b>	7	5	12
	<b>Number of 'community advocates' trained</b>	165	130	295

During the last 12 months the SCPP delivered 637 health awareness sessions across Tanzania and Malawi, to an audience of 17,290 people, including patients, their friends, families, teachers and community representatives. In Tanzania, 394 sessions were delivered to an audience of 12,557 people, with an average of 1.6 awareness sessions per clinic. In Malawi, we delivered 243 sessions to an audience of 4,733 people, with an average of 1.7 sessions per clinic. We also distributed a total of 10,249 and 2,507 education booklets to people with albinism in Tanzania and Malawi respectively.

During 2023, 7 Community Advocate Training events were delivered across 4 new regions of Tanzania (Mbeya, Iringa, Ruvuma and Ngombe), and 5 training events were delivered across 5 new districts of Malawi (Ntcheu, Dedza, Zomba, Chikwawa, and Chiradzulu). These workshops targeted health professionals and support staff such as Health Surveillance Assistants, Social Welfare Officers and District Committee members of Albinism Associations to protect and advocate for the welfare of people with albinism in between clinic cycles. Across both countries 295 people were trained during 2023.



*A mother departs hospital protecting her child from the sun using an umbrella she was given during a Skin Cancer Prevention Clinic*

## 4.9 Stakeholder Training

As well as providing health education for patients and families, the SCPP promotes systemic change in Tanzania and Malawi by strengthening the ability of health workers to prevent and treat skin cancer in people with albinism.

During 2023 we delivered 29 stakeholder engagement workshops (24 in Tanzania and 5 in Malawi). Each workshop took place prior to launching new SCPP clinical services in new regions and districts of each country. These workshops are designed to introduce the SCPP to relevant stakeholders, map hospitals, health centres and patient populations, so we can identify optimal clinic locations prior to launching the SCPP. The workshops also include sessions on understanding albinism, importance of health education, clinic set-up, data collection and referral management for different stakeholder groups. Participants attending ranged from Regional Administrative Secretaries, District Medical Officers, District Social Welfare Officers, Special Education Officers, Medical Officers in-charge, and district and regional representatives of the Tanzania Albinism Society (TAS) and Association of Persons with Albinism in Malawi (APAM).

This year we delivered training to 241 health personnel; 64 of these were in Tanzania and 177 in Malawi. Trainees included Dermatology Officers, Surgical Officers, Medical Assistants, nurses and Health surveillance Assistants. Training in both countries consisted of 1 or 2 theoretical classroom-based training days, and an additional 3-5 practical clinic or theatre based training days for Dermatology and Surgical Officers.

In December, as part of our clinical training we delivered a week-long Surgical Camp in Malawi. Training was led by Irish Plastic Surgeon Dr Patricia Eadie, Standing Voice Advisory Board member and GP Dermatologist Dr Mark Wheeler, Malawian Plastic Surgeons Dr Tilende Chokotho, Dr Daniel Getachew and Dr Bright from Queens Central Hospital. The event trained 14 Surgical Officers. In addition 22 people with albinism received life saving skin cancer surgery, and 3 people received palliative support and counselling. The Surgical Camp was also supported by 9 hospital support staff from Phalombe District Hospital (including nurses, theatre and ward staff), and 6 staff from Standing Voice Malawi.

Across all our training initiatives delivered in 2023 we strengthened the capacity of 336 key duty bearers in Tanzania and 307 in Malawi.



*Photo: Surgical Training team at Phalombe District Hospital, Malawi in December 2023*

Photo: Trainee Clinical Officers practice performing surgical excisions using skin pads during a surgical training workshop in Mwanza, Tanzania in March 2023



The table below shows the large number of actors working across the programme. Today there are 2,034 people involved in delivering the SCPP.

By the end of 2027 we aim to have trained and mobilised over 2,500 frontline workers to lead the delivery of this programme.

SCPP stakeholders	Tanzania	Malawi	Total
<b>Dermatologists and Dermatology Officers</b>	41	25	66
<b>Albinism Association leaders</b>	276	136	412
<b>Social Welfare Officers &amp; Health Surveillance Assistants</b>	171	96	267
<b>Other health personnel: Clinicians, Medical Assistants, Nurses, Surgeons, Histopathologists</b>	228	317	545
<b>Regional &amp; District Medical Officers</b>	114	17	131
<b>First responders / counsellors</b>	22	28	50
<b>Optometrists</b>	19	-	19
<b>Special Education Officers (Regional &amp; District)</b>	114	-	114
<b>Teachers</b>	388	-	388
<b>Tailors</b>	17	-	17
<b>Pharmacists</b>	8	17	25
<b>Total</b>	<b>1,398</b>	<b>636</b>	<b>2,034</b>

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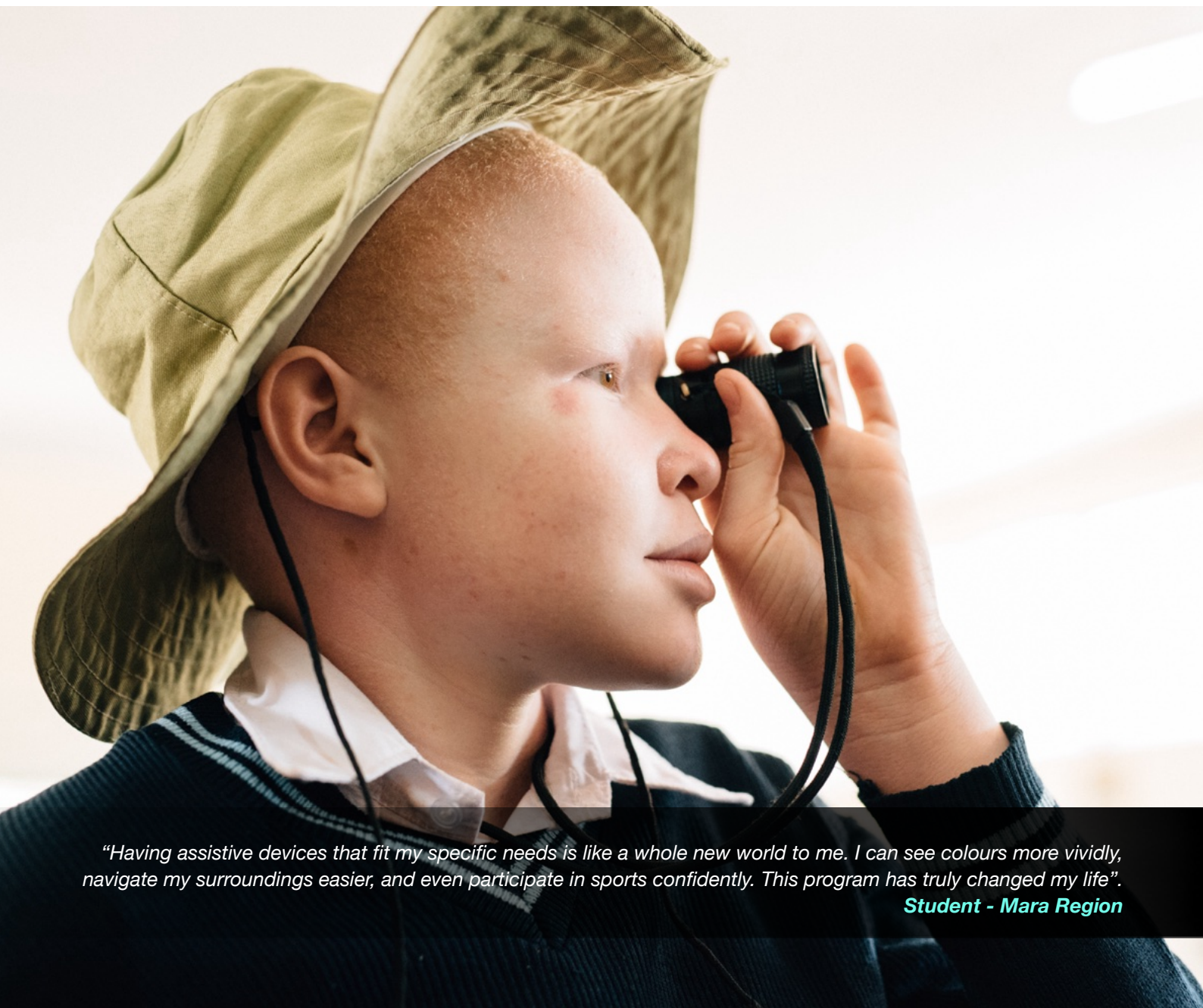
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## 5. VISION AND EDUCATION PROGRAMME

People with albinism are visually impaired as a result of their melanin deficiency. Untreated, visual impairment can undermine educational outcomes and restrict professional opportunities for people with albinism in Africa, damaging their economic security and forcing many into outdoor labour as subsistence farmers, where the risk of skin cancer is high. In Tanzania and Malawi, limited affordability and availability of specialist optometry services together with systemic discrimination mean most people with albinism do not access the vision care and education they need. Most teachers are also not trained to understand or manage the visual impairment of students with albinism in school.

Since 2014, Standing Voice has been delivering a clinical programme of care, education, and training to improve the vision of people with albinism and strengthen the skills of optometrists and teachers to better cater for their needs. Focusing mainly on students, the programme delivers a network of eye-clinics that provide specialist low vision examinations and assistive devices including monocular telescopes, prescription glasses, Sunglasses, health education and resources.

The Vision and Education Programme (VEP) is conducted in partnership with the Government of Tanzania and a range of civil society actors. As of Dec 31st 2023, there were 3,877 people with albinism registered in the VEP across 11 regions of Tanzania, and the programme will expand to Malawi in 2024.



*“Having assistive devices that fit my specific needs is like a whole new world to me. I can see colours more vividly, navigate my surroundings easier, and even participate in sports confidently. This program has truly changed my life”.*

**Student - Mara Region**

## 5.1 Key Achievements in 2023

### → Total people with albinism supported: 2,725

The Vision Programme delivered seven large-scale eye clinics in 2023, serving 2,735 people with albinism. Patients were mobilised from across eleven regions in Tanzania, which included Mwanza, Arusha, Dar es Salaam, Dodoma, Tabora, Singida, Shinyanga, Ruvuma, Ngombe, Kilimanjaro and Pwani. All patients received a one-to-one consultation and eye examination, education on albinism and visual impairment, and resources and devices to support the management of low vision in daily life.

### → Total assistive vision devices distributed: 10,717

Throughout 2023, we distributed 10,717 assistive devices including 1,870 pairs of prescription glasses, 5,483, pairs of sunglasses, 1,523 monocular telescopes, 1,744 glasses cases and 97 dome magnifiers.

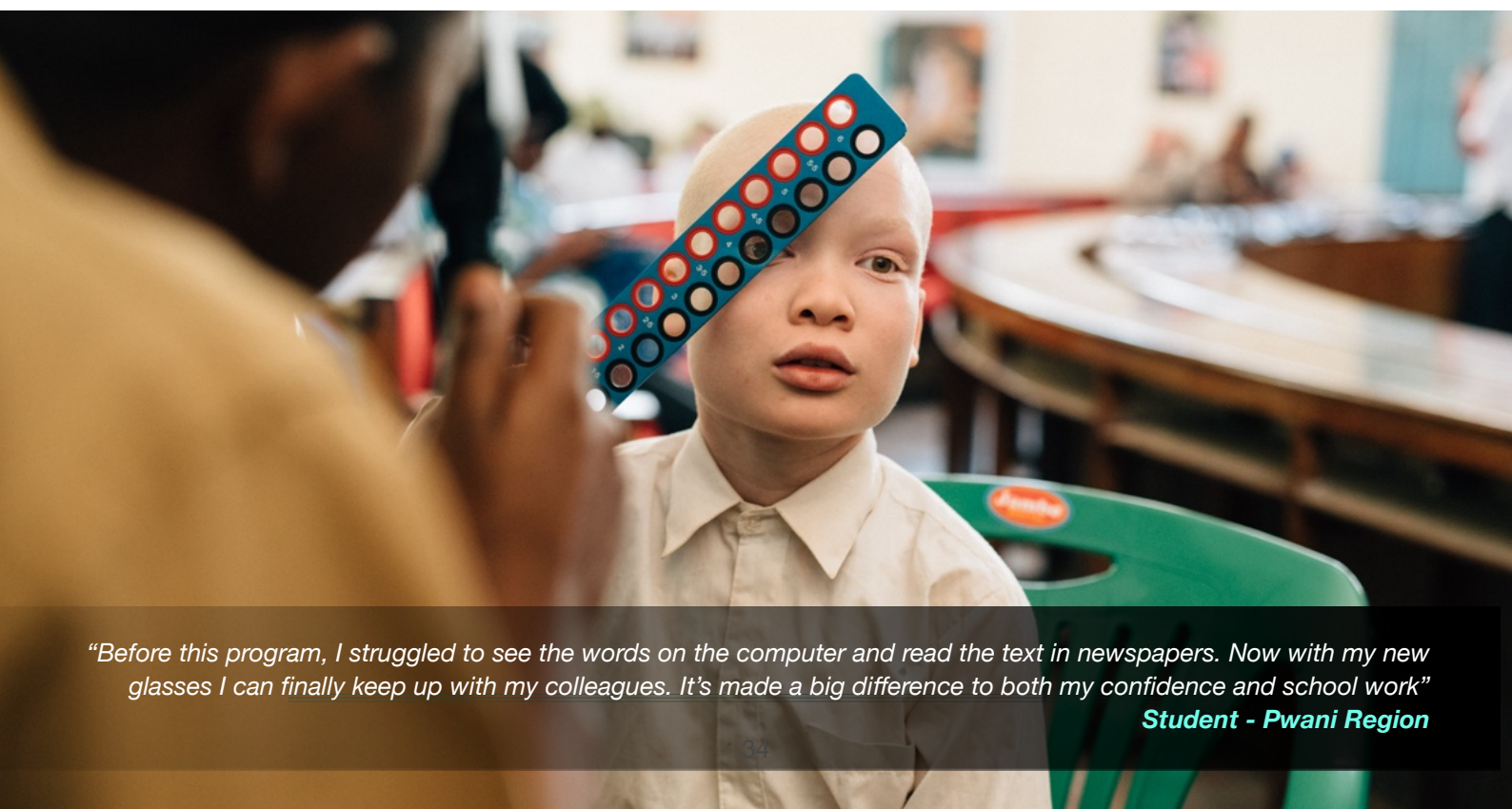
### → Teachers trained: 102

Throughout 2023, the Standing Voice Team delivered specialist training on albinism and inclusive education for 102 teachers across 12 schools in Tanzania. In each of these schools, our staff conducted 'barazas' and parades to build knowledge of albinism across the student body.

### → Students reached through seminars and school outreach 28,572

In addition to eye clinics, we coordinated awareness and understanding albinism seminars in schools across Tanzania. During these events special talks were delivered to engage students and promote positive messages around albinism and personal achievement. Conducted in parallel with our main clinical programme, this series of events delivered one-to-one support for 1,431 students with albinism while delivering wider sensitisation to 28,572 students across 46 schools (including the 12 schools we trained teachers in during 2023). Alongside these inspirational talks, we run talent competitions with prizes, interactive seminars, book readings, and film screenings. This year schools and students across Ukerewe Island were invited to visit the Umoja Training Centre where they received further training on albinism, alongside access to our community library stocked with Swahili and English books.

Please see the 2023 Annual Vision Programme Report for a detailed update of the programmes impact this year.



*"Before this program, I struggled to see the words on the computer and read the text in newspapers. Now with my new glasses I can finally keep up with my colleagues. It's made a big difference to both my confidence and school work"*

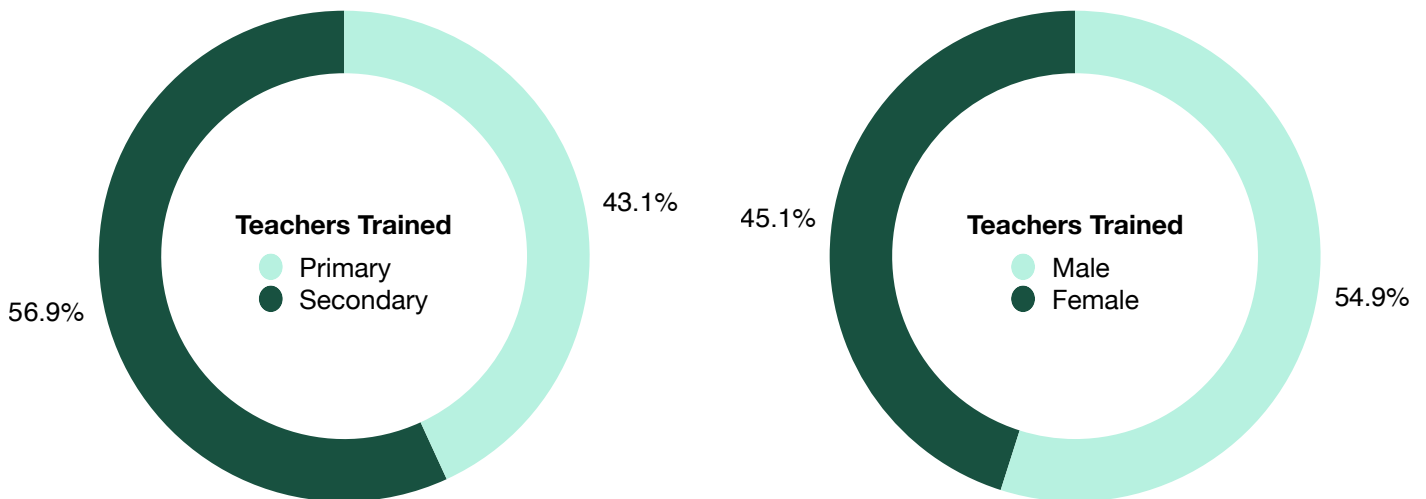
**Student - Pwani Region**

## 5.2 Impact on Education

### 5.2.i TEACHER TRAINING

As well as providing direct clinical care, the Vision Programme aims to achieve systemic change in Tanzania by strengthening the capacity of teachers to understand and mitigate the effects of visual impairment on the education of students with albinism. This is critical for enabling the next generation of people with albinism to reach their educational and professional potential, breaking the long-term cycle of stigma.

	Teachers Trained in 2023		
	Male	Female	Total
Primary	25	19	44
Secondary	31	27	58
Total	56	46	102



Throughout 2023, Standing Voice partnered with 12 schools across four regions of Tanzania to provide specialist training for 102 teachers. Tasked with monitoring and promoting the welfare of students with albinism, these teachers act as Vision Ambassadors who create a culture of respect, solidarity and mutual accountability in safeguarding the rights of these students in their schools; they also function as an important referral link with the main clinical service, reporting to Standing Voice on students' ongoing vision needs and ensuring the correct use and maintenance of prescribed assistive devices. This reciprocity between teacher training and clinical care is strengthened by the increasingly prominent role of optometrists, who travel to schools with the Standing Voice Team to support the delivery of teacher training and provide follow-up care to students in the wake of our main clinical service.

In partnership with Standing Voice, Vision Ambassadors and senior leaders across these 12 schools developed and implemented tailored action plans to improve the educational participation and welfare of students with albinism. Remedial measures have included:

- the production of large-font examination papers, repainting of blackboards, improvement of classroom lighting systems, and adjustments to classroom seating positions to alleviate barriers to accessibility for students with albinism

- the provision of additional after-class support for students with albinism
- the delivery of awareness-raising assemblies on albinism
- the promotion and monitoring of sun protection measures, including the application of sunscreen and use of sun protective clothing by students with albinism
- the encouragement of students to respect their peers with albinism and support their needs, for example by reading aloud from textbooks or the blackboard

Through the implementation of these measures and promotion of greater understanding of the rights and needs of people with albinism across these 12 schools, we estimate that 5,500 students and an additional 11,000 family members will be sensitised. Focus group discussions have moreover revealed a broad improvement in the self-reported educational welfare and attainment of students with albinism, while likert-scale surveys have shown growth in teachers' understanding of albinism as well as their confidence in responding to the needs of students with albinism. Key findings have also been disseminated to a range of stakeholders in Tanzania across the health and education sectors, civil society, media and local and national government, establishing a cross-sectoral dialogue around the needs of students with albinism and helping to embed these lessons in contemporary teaching practice.

Also in 2023 we were able to secure the donation of 3 large screen video magnifiers from the US that were donated to selected schools to support students with albinism in their final years of education.

*"Prior to receiving training, I knew very little about the needs of students with albinism. I can now confidently share my knowledge on albinism and low vision with the entire student community."*

**Teacher**



*"I am proud to be part of a team educating society about albinism, and playing my part in inspiring young children with albinism to reach for their dreams. These are opportunities I was denied as a child, and I am determined to ensure the next generation do not face the same challenges I did"*

**Mashaka Tutu - Standing Voice Tanzania - Staff Member**



*“I’m so proud of the work we are doing at Standing Voice to train more optometrists as experts in low vision management. Together we are bringing transformational eye care to thousands of students with albinism and giving them the tools and knowledge they need to excel in life.”*

**Dr Abdi Nyembo, Head of Optometry and Training**

### 5.3 Training of Optometrists

To strengthen access to eye care for people with albinism in Tanzania, Standing Voice partners with the Tanzania Optometric Association, the Kilimanjaro Christian Medical Centre School of Optometry and a network of international experts to train optometrists in the diagnosis and treatment of low vision in this population. There were 17 optometrists trained during 2023 of which 5 were new to the programme. A total of 19 Optometrists now support the deliver of the VEP in Tanzania.

As part of this ongoing initiative, we held a training workshops for Optometrists in Arusha in August and Mwanza in October. This included reviewing core theory on the complex vision needs of people with albinism, including refractive, prescribing and dispensing strategies, and how to deliver specialised vision screening. The days that followed allowed optometrists to practise their newly honed skills in a clinical environment, using our electronic patient management system CommCare and working directly with patients.

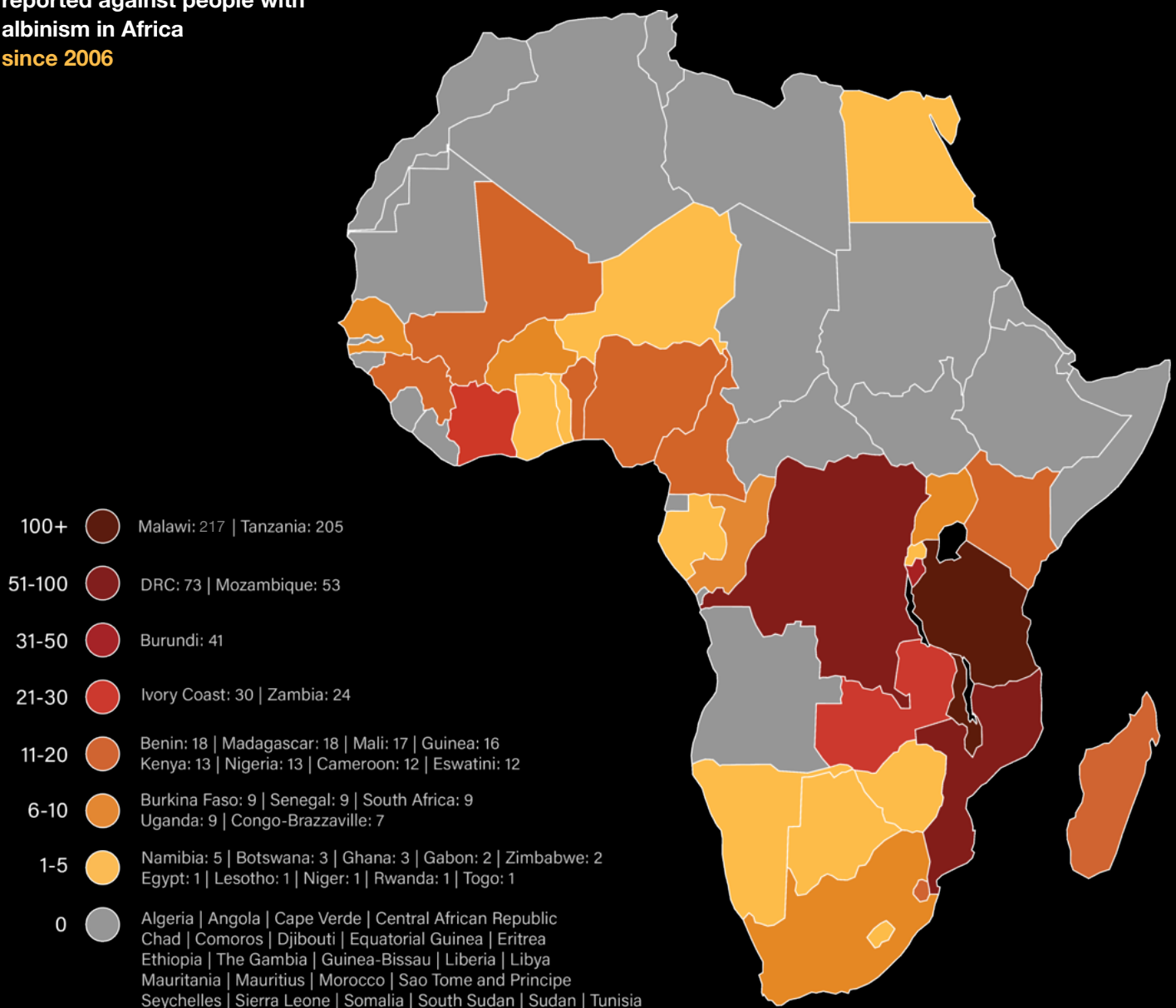
We are grateful for the tenacity and leadership of Dr Abdi Nyembo, an optometrist and tutor at the Kilimanjaro School of Optometry, who oversees the delivery of patient care and optometric training. In Mwanza in October we were delighted to be joined by Dr Rebecca Kammer, a world-leading expert in the low vision of people with albinism and long-term strategic advisor and director of the Vision Programme. We also extend our thanks to Professor Susan Primo, Director of Optometry and Vision Rehabilitation Services at the Emory Eye Center and Professor of Ophthalmology at the Emory University School of Medicine. Susan joined our team to support training in Arusha this year and will continue to provide support to clinical development of the Vision Programme moving forward.

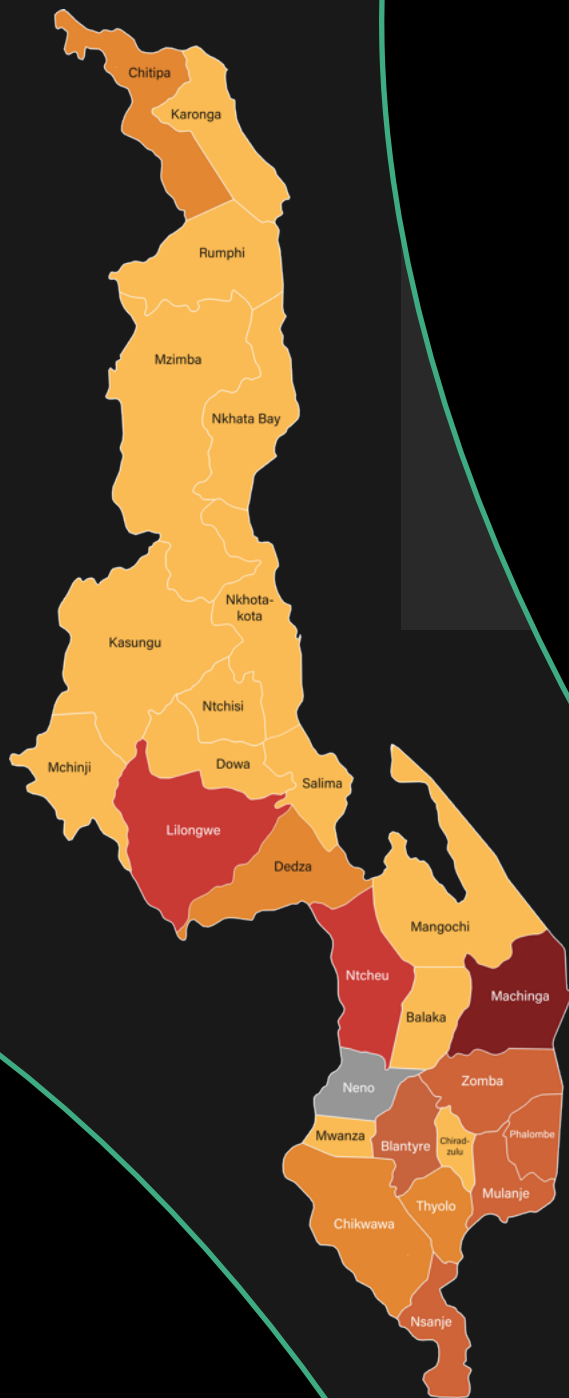
## 6. WELFARE AND SOCIAL PROTECTION PROGRAMME

### 6.1 The Issue

People with albinism are a violently persecuted minority in many African countries. Stigmatised for their unique appearance, many people with albinism are denied opportunities, excluded from services and subjected to damaging myths and misconceptions. In the worst cases, people with albinism are abducted, mutilated, raped and murdered: all because of the colour of their skin. As of December 2023 Standing Voice has documented 819 human rights violations against persons with albinism in Africa. Tanzania and Malawi have been the continental epicentres of these atrocities; together, these two countries account for half of all human rights violations reported against people with albinism across the continent since 2006. In 2023 violent attacks against people with albinism in Malawi continued to escalate, with a string of attempted abductions and grave violations reported in southern and central districts of the country. 1 in 6 people with albinism living in Machinga District of Malawi have been victim to attack.

**824 human rights violations**  
reported against people with  
albinism in Africa  
since 2006





## MALAWI

### 217 human rights violations

reported against people with albinism since 2006

- 30+ ● Machinga: 38
- 16-30 ● Ntcheu: 17 | Lilongwe: 17
- 11-15 ● Zomba: 15 | Mulanje: 14 | Phalombe: 15 | Blantyre: 13 | Nsanje: 11
- 6-10 ● Dedza: 9 | Chitipa: 8 | Thyolo: 8 | Chikwawa: 7
- 1-5 ● Mangochi: 5 | Balaka: 4 | Salima: 4 | Chiradzulu: 4 | Karonga: 3  
Mchinji: 3 | Mwanza: 4 | Ntchisi: 5 | Dowa: 4 | Kasungu: 2  
Mzimba: 2 | Nkhata Bay: 2 | Nkhatakota: 2 | Rumphu: 1
- 0 ● Neno

### Most recent attacks:

#### 3rd September 2023

attempted abduction of a one-year old boy with albinism in Lilongwe district, Malawi

#### 5th July 2023

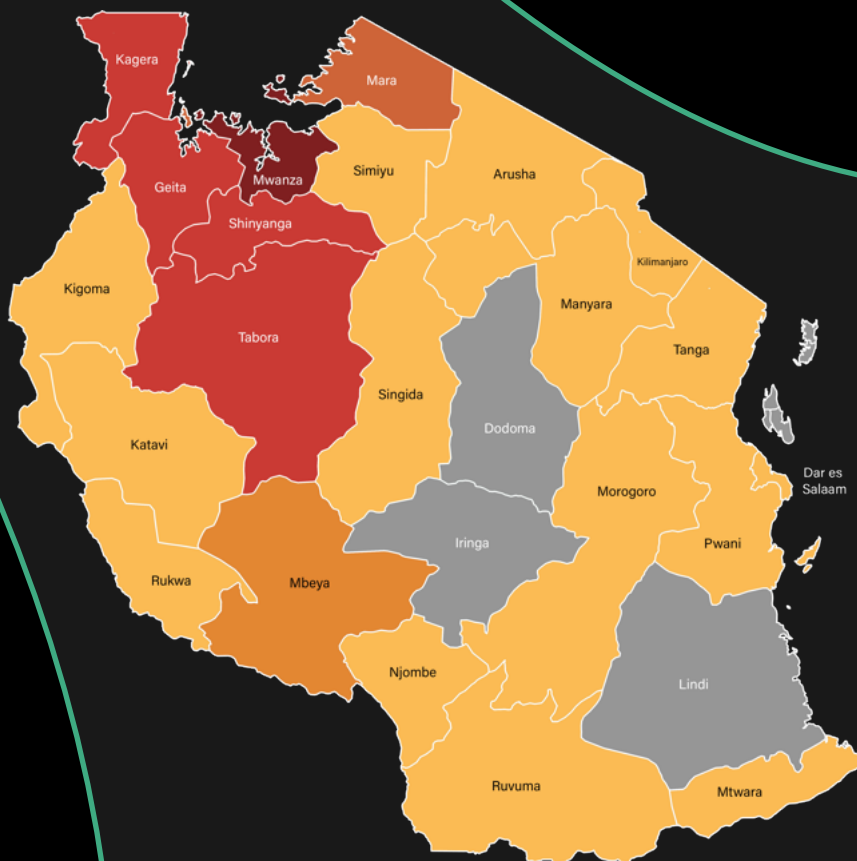
attempted attack against a 12-year old girl with albinism in Dowa district, Malawi

## TANZANIA

### 205 human rights violations

reported against people with albinism since 2006

- 30+ ● Mwanza: 55
- 16-29 ● Kagera: 24 | Geita: 17 | Shinyanga: 17 | Tabora: 16  
Unknown locations 16
- 11-15 ● Mara: 14
- 6-10 ● Mbeya: 6
- 1-5 ● Rukwa: 5 | Kigoma: 4 | Morogoro: 4 | Pwani: 4  
Arusha: 3 | Dar es Salaam: 4 | Simiyu: 3 | Tanga: 4  
Njombe: 2 | Katavi: 1 | Kilimanjaro: 1 | Manyara: 1  
Mtwara: 1 | Ruvuma: 1 | Singida: 1 | Songwe: 1
- 0 ● Dodoma | Iringa | Lindi | Zanzibar | Pemba



Alongside the ever-present threat of violent abuse and entrenched discrimination the majority of people with albinism we work with in Tanzania and Malawi face additional challenges to access education, housing, financial security, justice and political representation. Many are survivors of trauma and require specialised support to navigate this range of challenges.

Operating throughout Tanzania and Malawi, the Standing Voice First Response Team works to identify, intercept and rectify cases of abuse or discrimination against people with albinism and their families. Comprising local Standing Voice staff, social welfare professionals and individuals with first-hand experience of albinism-related stigma, the team has spent the last three years undergoing a programme of training with Dr Mark Fish, a world-leading expert in trauma recovery and member of the Standing Voice Advisory Board. The First Response Team is a lifeline for the most vulnerable individuals supported by Standing Voice. Its key pillars of interventions in 2023 included:

## 6.2 Albinism Helpline

Indicator	Tanzania	Malawi
Regions where people with albinism have access to a helpline	20	17
Calls received through helpline	2,269	910

In 2023 we continued to develop and operate two dedicated toll-free helplines, available to people with albinism and their families to report incidents of abuse and share any concerns about their health, welfare or security. Our team assesses callers’ needs and determines the appropriate course of action, such as over-the-phone advice, referral to an existing Standing Voice programme or to a specialist partner, or alerting of law enforcement in cases where an imminent threat to life is identified. The helpline is accessible to people with albinism across 20 regions of Tanzania and 17 districts of Malawi.

Since its establishment in 2021, our helplines have received 2,269 calls in Tanzania and 910 calls in Malawi. The helpline is advertised in all districts and regions where the Skin Cancer Prevention Programme operates. The most common reasons for contacting the helpline are reports of abuse, actual or anticipated threats to security (such as attacks), urgent medical care, emotional support, access to education, food and economic security.



### 6.3 Advocacy and Access to Justice

To help protect people with albinism from discrimination and violence we have worked hard to raise awareness, build greater understanding about albinism in communities, and create a climate where rights of persons with albinism are recognised and respected at local, national and global levels.

In 2023 Standing Voice worked with communities throughout Tanzania and Malawi to challenge harmful myths and misconceptions about albinism and strengthen security for people with albinism through the delivery of training aimed at building a society equipped to improve access to services, promote social inclusion and report abuses. To achieve this objective we continued to deploy a broad spectrum of activities including educational seminars, [assemblies](#), workshops, [parades](#), film screenings, [installations](#), [exhibitions](#) and interactive community-based [theatre](#), [comedy](#) and [music](#).

Standing Voice continues to push beyond national boundaries to generate global accountability for the welfare of people with albinism in Africa. Through our special consultative status with the Social and Economic Council of the United Nations, we are an active contributor to advocacy on albinism throughout the UN system: sharing reports of human rights abuses, issuing recommendations based on our data, and collaborating with the mandate of the Independent Expert on Albinism appointed by the United Nations. We have called for greater international action on this issue and elevated the global profile of albinism in Africa through a series of high-profile films, including our founding documentary [In the Shadow of the Sun](#) and the acclaimed BBC production [Born Too White](#).



## 6.4 Counselling and Emergency Tailored Support

Indicator	Tanzania	Malawi
Regions / districts where PWA have access to counselling at clinics	3	4
PWA with access to counselling service at clinics	1,871	665
People counselled through peer-to-peer counselling at clinics	152	152
Number of clinics with Counselling delivered	36	32
PWA receiving tailored and emergency support	108	49

During 2023 we continued to expand peer counselling at Dermatology clinics throughout Tanzania and Malawi, providing safe and confidential spaces for people with albinism and their families to speak freely about their needs and concerns, process trauma, build confidence and access referral for specialist services where required. By the end of 2023, counselling was accessible to 1,871 people with albinism across three regions of Tanzania and to 665 people in four districts of Malawi. Across both countries a total of 304 individuals received counselling during the reporting period via delivery of 68 clinics. Of the 152 people visiting counselling stations during 2023 in Tanzania 82% were female. Of the 152 clients who received counselling at clinic in Malawi during 2023 58% were female.

For the most vulnerable people we work with – many of whom carry acute psychological trauma and have survived witchcraft-related atrocities – our First Response Team provides a package of emergency support. This can include relocation to safe-housing, home security improvements; livelihood and food security support; urgent medical intervention; psychosocial, dermatological and palliative healthcare; facilitation of trauma recovery or family reconciliation; and direct advocacy interventions in situations of risk, conflict or exclusion. Across both countries 157 people with albinism received tailored support during 2023. This included ongoing support to 22 survivors of attack and 21 of their family members,

During 2023 this area of our was funded by the United Nations Voluntary Fund for Victims of Torture, the European Commission and Foundation Pierre Fabre.



- 1 in 6 PWA in Machinga Malawi have been victim to attack
- 62% of survivors we are working with are under 15 years old
- 50% of our highest risk survivors are under 10 years old

## 6.5 Livelihoods Training and Art Therapy

	Indicator	Tanzania
<b>People with albinism receiving ongoing skills development or income generation support</b>		58
<b>Community members benefitting from the Umoja Training Centre (UTC)</b>		29,822
<b>Number of school children reached by the UTC</b>		46
<b>UTC tailors trained</b>		18
<b>Hats produced by UTC tailors</b>		13,350
<b>Hats produced since initiative begun (2021)</b>		25,183

In 2014, Standing Voice established the Umoja Training Centre (UTC): a facility providing formal training initiatives to promote integration and shared prosperity for people with albinism and their peers and families across Tanzania's Lake Zone. Home to the Ukerewe Albinism Society and a growing number of community groups, the UTC is a hub of business activity, skills development, and therapeutic rehabilitation for survivors of discrimination and violence. The centre provides a second chance for people with albinism who may have missed out on the opportunity of formal education while growing up. With English language classes and the only library on Ukerewe Island, the UTC maintains an extensive programme of school outreach and is an important resource for raising awareness of albinism and strengthening education locally.

In 2023, the UTC continued to support the capacity development of a wide range of community groups and 58 individual trainees with albinism and their families. Disciplines included tailoring, soap-making, batik, photography, radio production, music, and the performing and visual arts. Through the support of the Foundation Pierre Fabre, we have been able to continue to nurture the development of UTC tailors, who to date have manufactured 13,350 wide-brimmed hats for distribution for free to people with albinism through 206 hospitals and health centres engaged in the delivery of the Skin Cancer Prevention Programme in Tanzania and Malawi. During 2023 a total of 29,822 community members from across Ukerewe Island benefited from the UTC and its community development activities.

Activities at the UTC include group therapy, a community library and garden, tailoring, soap making, batik, radio production, photography, art, music and drama



## 6.6 Human Rights Training

A key aim of our social protection and welfare programme is to strengthen the capacity of key duty bearers to recognise, monitor and protect the human rights of people with albinism in Tanzania and Malawi. Through delivery of workshops and equational clinic based seminars, we are building a network of albinism ambassadors encompassing a range of stakeholder groups: the family and community members of people with albinism, health and welfare professionals, teachers, local government representatives, members of law enforcement and the judiciary, representatives of government ministries and national human rights institutes, media professionals, religious and traditional leaders and albinism association representatives. During 2023 this support was extended in Malawi through the support of the European Commission and the dleibver of our Ufulu Wanga Project in collaboration with YONECO and Beyond Sincere.

➔ **People with albinism and family members participating in rights-based training: 13,320**

Operating through dermatology clinics, the First Response Team delivered human rights training to thousands of people with albinism and their families and caregivers. The team leads educational seminars and distributes resources to build understanding of albinism and human rights and raises awareness of best practices for protecting and empowering families impacted by albinism.

By the end of 2023, 13,320 people had received this right-based training at clinics 12,577 of these were in Tanzanian 743 in Malawi.

➔ **Albinism Advocates trained: 295**

In 2023, through our partnership with the Foundation Pierre Fabre and the European Commission we trained a network of community based albinism advocates to mobilise, monitor and support the most at-risk people with albinism at the community level. These advocates include albinism association leaders, social welfare professionals and community health workers, many of whom are already engaged in the SCPP and play a critical role in the identification, mobilisation and management of patients in between clinic cycles.

During the reporting period **295** Albinism Advocates were trained and equipped to support and advocate for the rights of persons with albinism in communities across Tanzania and Malawi.



➔ A group of albinism advocates following a training event in Ntcheu, Malawi

## 6.7 Women's Albinism Action Group

Women with albinism and mothers of children with albinism face intersectional discrimination and are often uniquely vulnerable to poverty and violence. In Tanzania and Malawi, the myth that intercourse with a woman with albinism can cure infertility and AIDS places this population at disproportionate risk of sexual violence and contraction of HIV. Mothers of babies with albinism are often blamed when a baby with albinism is born, abandoned by their husbands and families and left with sole responsibility for the health, education and physical and economic security of their child. The abandonment of many mothers by their partners also restricts the ability of these women to participate in income-generating activities, further jeopardising the health and security of both mother and child.

Established in 2015 with the support of Standing Voice, the Women's Albinism Action Group (WAAG) is a registered community-based organisation run by and for mothers impacted by albinism based at the Umoja Training Centre in Tanzania. The group began as an informal collective, meeting to share their experiences and reflect on their challenges as women with albinism or mothers of children with albinism. Over time, bonds of trust and solidarity were strengthened and the group now meets regularly to provide peer support and conduct community advocacy. The group works with Standing Voice and the Tanzania Albinism Society to identify and counsel new mothers of babies with albinism, travelling to communities where stigma is rife to raise awareness of albinism and advocate for the safety and inclusion of all families impacted by the condition.

During 2023, the Women's Albinism Action Group delivered counselling, training and community outreach to build knowledge and debunk myths about albinism in schools, health centres, and a variety of community settings, sensitising 5,771 people. In addition to the Standing Voice helpline, the WAAG also operates its own dedicated helpline to support women and girls impacted by albinism and has supported 795 callers to date. The WAAG has reached 12,205 people through its work since 2021.



- **Established at the UTC** as a safety and support mechanism for women impacted by albinism
- The WAAG registered as a **community-based organisation in 2021**
- The WAAG provides **peer counselling** and operates a **helpline** for women and mothers impacted by albinism; delivers **albinism training for welfare professionals**; and conducts **community outreach** to build public awareness of the rights and needs of people with albinism
- The WAAG has sensitised **12,205** people on albinism since 2021

## 7. SPECIAL EVENTS

This year we have been very active in advocating for the rights and needs of people with albinism around the world. Throughout 2023 Standing Voice leadership teams were invited to present its work during workshops, international conferences and symposiums.

In February 2023 our team in Tanzania and Malawi joined a Human Rights workshop organised and hosted by the African Albinism Network (AAN) in Dar es Salaam, attended by albinism organisations and human rights defenders from 14 African countries. The training focused on building awareness of the effective use of the AU Plan of Action on Albinism, human rights advocacy, and reporting strategies to develop and domesticate the Plan of Action into National Action Plans on Albinism. In March SV Malawi joined a National Engagement Meeting on Albinism in Lilongwe convened by the Government of Malawi and attended by key actors working on albinism in the country. Also in March we welcomed the European Union Ambassador to Malawi his Excellency Rune Skinnebach and Deputy Minister of Health Hon. Hakima Daudi in Dedza, Malawi to officially launch the start of our new EU funded project Ufulu Wanga (Our Rights). In June, to commemorate International Albinism Awareness Day (IAAD) we held special events across Tanzania, Malawi and the UK. This included delivery of free dermatology and low vision screenings in Ruvuma in Tanzania, and Dowa in Malawi. In June, also to mark IAAD Standing Voice was proud to support the Lazarus Music Festival. Bonface Massah, SV Malawi Executive Director joined Lazarus and his team as they travelled across four districts of Southern Malawi to raise awareness about albinism and bring Lazarus's music to the people. Bonface joined Lazarus on stage to speak about albinism and the work of SV. On the 10th October Bonface joined a meeting of SADC to validate a framework for the Effective Cross Border Policing of Crimes against Persons with Albinism by the Southern African Development Community (SADC). In November, Bonface travelled to Namibia to commemorate National Albinism Day and lead part of a Stakeholder Engagement and Learning Forum to support the Development of the National Action Plan for Persons with Albinism in Namibia. On the 5th December, as part of a special Disability Inclusion event hosted by the French Embassy in Dar es Salaam Tanzania, Alex Magaga, SV Tanzania Operations Manager joined Christophe Przybylski, the Scientific Director of the Foundation Pierre Fabre to present on our joint programme to mark International Day of people with disabilities. On the 19th December Bonface Massah, SV Malawi ED was invited to the EU Delegation in Malawi to give a 10 minute oral presentation on 'The State of Human Rights in Malawi' to Members of the EU Parliament - Committee on International Relations.

We also held press events and celebrations to mark Skin Cancer Awareness Month and World Sight Day. Throughout the year our projects were visited by representatives from the President's Office TAMISEMI, the Prime Minister's Office, the National Eye Coordinator and other Ministry of Health representatives, Regional and District Education Officers, and national and regional leaders of the Tanzania Albinism Society and Association of Persons with Albinism in Malawi. These events were documented on radio and TV stations across Tanzania and Malawi.



## 8. DATA MANAGEMENT

In 2023 we conducted several activities to further develop our data collection tools and strengthen the roll out of our custom built electronic health information system across both countries. During the reporting period the system was active and supporting delivery of all SCPP and VEP health services across Tanzania and Malawi, as well as supporting an albinism programme in Rwanda. In August we welcomed partners Source of the Nile for Persons with Albinism from Uganda to Tanzania where we showcased the database with the aim supporting SNUPA to develop their data management in Uganda in 2024.

During 2023 we designed new tools to support the Welfare programme, including delivery of risk assessments at clinics. These new tools underwent field testing on paper throughout the year and will undergo transition to our electronic data capture system (Commcare) in 2024. During the reporting period we purchased 40 new tablets to support the ongoing expansion of health services scheduled over the next 2 years.

In both countries, we delivered further training to health professionals in the use of our data management system. These individuals included Dermatologists, Dermato-Venereology Officers, Clinical Officers, Medical assistants, Optometrists and SV staff. Today, there are 151 personnel actively using the system in the field.

	No. of people trained
<b>Tanzania</b>	69
<b>Malawi</b>	82
<b>Total</b>	<b>151</b>



## 9. FUNDING MATTERS

### GRANT-MAKING POLICY

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The charity's policy is to make grants to collaborating organisations who are in need of funds to deliver a service in partnership with Standing Voice. On occasion the trustees may decide to give a grant to a beneficiary organisation that is not working in partnership with Standing Voice, but is working towards a shared objective of the charity.

In line with our current activities the organisation or service funded must promote the wellbeing and social inclusion of people with albinism in Africa through advancing health, education, welfare or community-based projects and services.

All grants are awarded on the condition of robust accounting and financial reporting standards; strength of internal policies and procedures (including safeguarding, finance and procurement policies); past records of grant management and successful implementation; and compliance with all relevant regulations and international standards as defined by Standing Voice in its grant contracts.

### FUNDRAISING ACTIVITIES IN THE UK

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Standing Voice applies for grants from trust funds, grant-giving foundations and institutions, and corporate donors. Standing Voice also raises funds donated by individuals reached through direct approaches and by holding planned fundraising events and campaigns.

The charity's principal sources of funding during the year have consisted of grant funders and a group of committed philanthropists donating to specific projects.

Throughout 2023 we were proud to be funded by many innovative Foundations and Trust funds including the Foundation Pierre Fabre (FPF), the European Commission (EU), the International Foundation for Dermatology (IFD), the International League of Dermatological Societies (ILDS), the United Nations Voluntary Fund for Victims of Torture (UNVFVT), Deloitte Community Fund, University of Cambridge, the Sir Halley Stewart Trust, the Bilton Foundation, the John Armitage Charitable Trust (JACT), the HCD Memorial Fund, Inside the Same, The Edge, Mite, Wings of Support, Free A Girl, Esther Ireland, the Evan Cornish Foundation, the Souter Charitable Trust, African Albinism Foundation, the Reed Foundation and many others including those who wish to remain anonymous.

The trustees extend their sincere gratitude to all individuals and grant-givers who have donated to the organisation this year to ensure we continue our vital work.

### FINANCIAL PERFORMANCE

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Income during the period 1st January 2023 to 31st December 2023 amounted to £1,192,750 (January 2022-December 2022: £911,951). Voluntary income was £1,184,639 (2022: £911,875). Of the total income, £1,110,711 (2022: £822,199) was restricted and £82,040 (2022: £89,752) was unrestricted. The restricted income consists of donated funds from grant funders and individuals. £484,658 (2022: £377,112) of restricted funding was carried forward. Unrestricted income was mainly from individual donations.

Expenditure amounted to £1,070,753 (2022: £777,946) of which £1,008,458 (2022: £715,371) was project expenditure, £47,505 (2022: £56,600) was fundraising expenditure and £14,790 (2022: £5,975) was governance costs. Of the total expenditure, £1,003,165 (2022: £706,978) was restricted expenditure and £67,588 (2022: £70,968) was unrestricted expenditure.

Standing Voice exercises a policy of setting aside funds to cover 6 months of administration overheads as reserves, to cover core costs in the event of the organisation encountering a period of reduced income.

At the end of the financial year ending 31st December 2023 the charity carried forward a balance of £559,467 (2022: £437,470), of which £139,897.83 was available for overheads. The organisation also awaited funding responses from major grant funders. The trustees deemed reserve funds held to be sufficient, keeping in consideration the overheads budget allocations in restricted funds held, and the status of committed funding from new and existing donors due for disbursement in 2024 amounting to over £1,260,000.

## EXPENDITURE SUPPORTING KEY OBJECTIVES

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Standing Voice has been able to increase expenditure towards its life saving programmes in 2023 to £1,008,458. This has been vital at a time when our clients' needs are under pressure due to unstable global economic conditions, increasing risk of climate change-related disasters, and continued threat of attack against people with albinism. This increase in project expenditure (a £293,087 increase on 2022) has been carefully planned and deemed viable based on holding and securing new multi-year funding partnerships in 2023. Expenditure on our projects promoting the wellbeing and social inclusion of people with albinism is consistent with Standing Voice's objectives as defined in its governing constitution.

People with albinism in Tanzania and Malawi continue to benefit from capacity development; improved dermatological and ophthalmological health services; innovative trauma recovery interventions; increased access to education; and positive advances in local and international awareness on albinism resulting from Standing Voice's project activity. Additionally, through training and coordination of health, social care and education service providers we are building a sustained, scalable and locally driven response to this issue in both countries.

The charity's projects this year have grown substantially both in terms of geographical reach, and depth of the interventions being delivered across both countries of operation. Whilst growing the footprint of its work Standing Voice is progressively interlinking services, to ensure individual projects act as gateways for other essential services. Scaling up geographical reach, alongside investing in a holistic approach to our work has led Standing Voice to achieve its objective of combating human rights abuses against people with albinism by further advancing integration in society in 2023.



## 10. GOVERNANCE AND RISK

### FUTURE PLANS OF THE CHARITY

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In 2024, we will continue to expand the geographical reach of the Skin Cancer Prevention and Vision and Education Programmes in both Tanzania and Malawi. We will further accelerate our training of community leaders, teachers, health professionals, civil society groups, people with albinism and their families.

Through our long running partnership with the Foundation Pierre Fabre we will continue adapting our dermatology programme to allow for further phasing in and scale up of other complimentary services at clinics, specifically further expansion of psychosocial support and counselling, and strengthening of our toll-free albinism helplines. In Malawi the inclusion of these other forms of support will continue to be co-funded by the United Nations Voluntary Fund for Victims of Torture and the European Commission. By the end of 2024, counselling will be available at Dermatology clinics across three regions of Tanzania and eight districts of Malawi.

In 2024 we will enter the second year of our EU funded Ufulu Wanga Project. As well as supporting the continued scale up of dermatology, security and psychosocial support services in Malawi, next year the project will begin a community theatre and radio awareness campaign delivered in communities across Malawi in partnership with Theatre For Change, YONECO and Beyond Suncare.

Also in 2024 we will launch a new three year partnership with the Croda Foundation, who alongside our long-term funder and technical partner the Foundation Pierre Fabre they will co-fund the expansion of the Skin Cancer Prevention Programme in Tanzania with the aim of achieving national coverage by 2027.

During 2024 the expansion of our work across Tanzania and Malawi, will be combined with sustained efforts to continue catalysing action from national governments. We will achieve this through our advocacy work within and beyond these countries of operation, and through our position as Chair of the National Action Plan (NAP) on Albinism in Tanzania, and as a member of the NAP task force in Malawi.

### RISK

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The primary risk to the charity (and by association its clients) is insufficient staff capacity to meet the growing needs of our target group. As our services increase in scope and depth we are continually evidencing the complexity of people with albinism's life challenges and threats to their welfare. Meeting these challenges demands scaled up investment of resources to ensure we are able to sustain a high calibre and growing team.

We manage this risk through maintaining a varied portfolio of benefactor relationships, and through regular submission of new grant applications, and scrutiny of our expenditure pipeline. This allows us to plan for recruitment well in advance of new appointments, to ensure our team's development is delivered in line with funding commitments and strategy.

Additionally, Standing Voice consistently manages the risk of maladministration at the point of implementation through routine monitoring of our in-country teams in Tanzania and Malawi and deployment of robust control policies. Scheduled finance and activity reports are scrutinised upon submission, as a prerequisite for further fund disbursement by Standing Voice UK. Executive Management also monitors the flow of funds from the UK to our country offices through a two-step forex approval system, which ensures that any transfer between the UK and Malawi or Tanzania is reviewed and approved by two predetermined forex administrators at Standing Voice UK. Additionally, our UK trustees and management regularly visit Standing Voice local offices, partners and project sites to maintain visibility of all aspects of local operation, including potential risks that require new mitigation strategies.

## RESPONSIBILITIES OF THE BOARD OF TRUSTEES

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The Trustees are responsible for managing the affairs of the CIO and may for that purpose exercise all the powers of the CIO.

It is the duty of each charity trustee:

1. to exercise his or her powers and to perform his or her functions in his or her capacity as a trustee of the CIO in the way he or she decides in good faith would be most likely to further the purposes of the CIO; and
2. to exercise, in the performance of those functions, such care and skill as is reasonable in the circumstances having regard in particular to:
  1. any special knowledge or experience that he or she has or holds himself or herself out as having; and,
  2. if he or she acts as a charity trustee of the CIO in the course of a business or profession, to any special knowledge or experience that it is reasonable to expect of a person acting in the course of that kind of business or profession.

The Board of Trustees are responsible for complying with the requirements of the Charities Act 2011 with regard to the keeping of accounting records, to the preparation and scrutiny of statements of account, and to the preparation of annual reports and returns for submission to the Charity Commission.

## PUBLIC BENEFIT

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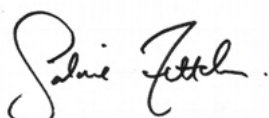
In accordance with section 17 of the Charities Act 2011 the Trustees confirm that they have had regard to the Charity Commission's guidance in relation to public benefit. The Trustees have referred to the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning the charity's future activities. In particular, the Trustees have considered how planned activities contribute to the aims and objectives they have set.

## TRUSTEES' DECLARATION

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There is no relevant information of which the charity independent examiner is unaware. Each Trustee has taken all the necessary steps that he/she ought to have taken as a Trustee in order to inform themselves of all relevant information, and to establish that the charity's independent examiner is aware of that information.

Approved by the Board of Trustees and signed on its behalf by:



**Sabine Zetteler**

Chair of the Board of Trustees

28/04/2023

## 11. ACCOUNTS

### 11.1 Independent Auditor's Report to the Trustees of Standing Voice

#### Opinion

We have audited the financial statements of Standing Voice (UK) (the 'CIO') for the year ended 31 December 2023 which comprise the Statement of Financial Activities, the Balance Sheet, Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the CIO's affairs as at 31 December 2023, and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

#### Basis of opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the CIO in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

#### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

#### Other information

The trustees are responsible for the other information. The other information comprises the information included in the trustees' report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated.

If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

### **Matters on which we are required to report by exception**

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the financial statements is inconsistent in any material respect with the trustees' report; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit.

### **Responsibilities of trustees**

As explained more fully in the trustees' responsibilities statement in trustees' report, the trustees are responsible for the preparation of financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the CIO's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the CIO or to cease operations, or have no realistic alternative but to do so.

### **Auditor's responsibilities for the audit of the financial statements**

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with regulations made under section 154 of that Act.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- We obtained an understanding of the legal and regulatory frameworks that are applicable to the CIO and determined that the most significant are the Statement of Recommended Practice 'Accounting and Reporting by Charities' (SORP 2019), in accordance with the Financial Reporting Standard applicable in the UK (FRS 102) applicable to smaller entities and the Charities Act 2011.
- We understood how the CIO is complying with those frameworks via communication with those charged with governance, together with the review of the CIO's documented policies and procedures.

- The audit team, which is experienced in the audit of charities, considered the charity's susceptibility to material misstatement and how fraud may occur. Our considerations included the risk of management override.
- Our approach was to check that the income from grants and donations were properly identified, grant payable were complied with the control procedures and related expenditure was appropriately charged. This included reviewing journal adjustments and unusual transactions.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.

### **Use of our report**

This report is made solely to the CIO's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the CIO's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the CIO and the CIO's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

A handwritten signature in black ink that reads 'Knox Cropper LLP'.

**Knox Cropper LLP**  
**Statutory Auditor**  
**65 Leadenhall Street**  
**London**  
**EC3A 2AD**

Date 28 October 2024

*Knox Cropper LLP is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.*

## 11.2 Statement of Financial Activities (SoFA)

Statement of Financial Activities (Incorporating an Income and Expenditure Account) for the period ended 31 December 2023:

	Notes	Unrestricted funds (£)	Restricted income funds (£)	Total 2023 (£)	Total 2022 (£)
<b>Income and endowments from:</b>					
Donations and legacies		73,928	1,110,711	1,184,639	911,875
Other trading activities		-	-	-	-
Income from investments		3,111	-	3,111	76
Income from charitable activities		-	-	-	-
Other income		5,000	-	5,000	-
<b>Total income and endowments</b>	<b>2</b>	<b>82,039</b>	<b>1,110,711</b>	<b>1,192,750</b>	<b>911,951</b>
<b>Expenditure on:</b>					
Raising funds		2,375	45,130	47,505	56,600
Charitable activities		50,423	958,035	1,008,458	715,371
Other expenditure		14,790	-	14,790	5,975
<b>Total expenditure</b>	<b>3</b>	<b>67,588</b>	<b>1,003,165</b>	<b>1,070,753</b>	<b>777,946</b>
<b>Net income/(expenditure) and net movement in funds for the year</b>		<b>14,451</b>	<b>107,546</b>	<b>121,997</b>	<b>134,005</b>
<b>Net income/(expenditure) before other recognised gains/(losses)</b>		<b>14,451</b>	<b>107,546</b>	<b>121,997</b>	<b>134,005</b>
<b>Other recognised gains/(losses)</b>					
Gains and losses on revaluation of fixed assets for charity's own use		-	-	-	-
Gains and losses on investment assets		-	-	-	-
<b>Net income/(expenditure) and movement in funds for the year</b>		<b>14,451</b>	<b>107,546</b>	<b>121,997</b>	<b>134,005</b>
<b>Total funds brought forward</b>		<b>60,358</b>	<b>377,112</b>	<b>437,470</b>	<b>303,465</b>
<b>Total funds carried forward</b>		<b>74,809</b>	<b>484,658</b>	<b>559,467</b>	<b>437,470</b>

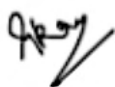
The Statement of Financial Activities includes all gains and losses recognised in the year. All the activities derive from continuing operations during the above periods.

## 11.3 BALANCE SHEET

Balance Sheet as at 31 December 2023

	Notes	Unrestricted funds (£)	Restricted income funds (£)	December 2023 (£)	December 2022 (£)
<b>Fixed assets</b>					
Tangible investments	4	-	29,507	29,507	7,932
Intangible investments					
<b>Total fixed assets</b>		<b>-</b>	<b>29,507</b>	<b>29,507</b>	<b>7,932</b>
<b>Current assets</b>					
Debtors and prepayments	5	25,519	-	25,519	100,474
Cash at bank and in hand		72,344	470,697	543,041	366,409
<b>Total current assets</b>		<b>97,863</b>	<b>470,697</b>	<b>568,560</b>	<b>466,883</b>
<b>Liabilities</b>					
Creditors: amounts falling due within one year	6	(23,054)	(15,546)	(38,600)	(37,345)
<b>Net current assets/(liabilities)</b>		<b>74,809</b>	<b>455,151</b>	<b>529,960</b>	<b>429,538</b>
<b>Total assets less current liabilities</b>		<b>74,809</b>	<b>484,658</b>	<b>559,467</b>	<b>437,470</b>
Creditors: amounts falling due after one year		-	-	-	-
Provisions for liabilities and charges		-	-	-	-
<b>Net assets</b>		<b>74,809</b>	<b>484,658</b>	<b>559,467</b>	<b>437,470</b>
<b>Funds of the charity</b>					
Unrestricted funds		74,809	-	74,809	60,358
Restricted income funds	7	-	484,658	484,658	377,112
Endowment funds		-	-	-	-
<b>Total funds</b>		<b>74,809</b>	<b>484,658</b>	<b>559,467</b>	<b>437,470</b>

The financial statements were approved and authorised for issue by the Trustees on 28/04/2024 and signed on their behalf by:



**Gurmeet Kaur**

Treasurer of the Board of Trustee

## 11.4 BASIS OF PREPARATION

Basis of preparation and accounting policies for year ended 31 December 2023

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) – Charities SORP (FRS 102) and the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

### 1. ACCOUNTING POLICIES

*This list of accounting policies has been applied by the charity.*

Incoming Resources	
<b>Recognition of incoming resources</b>	These are included in the Statement of Financial Activities (SoFA) when: <ul style="list-style-type: none"> <li>- the charity becomes entitled to the resources;</li> <li>- the trustees are virtually certain they will receive the resources; and</li> <li>- the monetary value can be measured with sufficient reliability</li> </ul>
<b>Incoming resources with related expenditure</b>	Where incoming resources have related expenditure (as with fundraising or contract income) the incoming resources and related expenditure are reported gross in the SoFA.
<b>Grants and donations</b>	Grants and donations are only included in the SoFA when the charity has unconditional entitlement to the resources.
<b>Tax reclaims on donations and gifts</b>	Incoming resources from tax reclaims are included in the SoFA at the same time as the gift to which they relate.
<b>Contractual income and performance-related grants</b>	This is only included in the SoFA once the related goods or services have been delivered.
<b>Gifts in kind</b>	Gifts in kind are accounted for at a reasonable estimate of their value to the charity or the amount actually realised. Gifts in kind for sale or distribution are included in the accounts as gifts only when sold or distributed by the charity. Gifts in kind for use by the charity are included in the SoFA as incoming resources when receivable.
<b>Donated services and facilities</b>	These are only included in incoming resources (with an equivalent amount in resources expended) where the benefit to the charity is reasonably quantifiable, measurable and material. The value placed on these resources is the estimated value to the charity of the service or facility received.
<b>Volunteer help</b>	The value of any voluntary help received is not included in the accounts but is described in the trustees' annual report.
<b>Investment income</b>	This is included in the accounts when receivable.
<b>Investment gains and losses</b>	This includes any gain or loss on the sale of investments and any gain or loss resulting from revaluing investments to market value at the end of the year.

## Expenditure and Liabilities

<b>Liability recognition</b>	Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to pay out resources.
<b>Governance costs</b>	Include costs of the preparation and examination of statutory accounts, the costs of trustee meetings and cost of any legal advice to trustees on governance or constitutional matters.
<b>Grants with performance conditions</b>	Where the charity gives a grant with conditions for its payment being a specific level of service or output to be provided, such grants are only recognised in the SoFA once the recipient of the grant has provided the specified service or output.
<b>Grants payable without performance conditions</b>	These are only recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the charity.
<b>Support Costs</b>	Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, e.g. allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

## Assets

<b>Tangible fixed assets for use by charity</b>	These are capitalised if they can be used for more than one year, and cost at least £500. They are valued at cost or a reasonable value on receipt.
<b>Investments</b>	Investments quoted on a recognised stock exchange are valued at market value at the year-end. Other investment assets are included at trustees' best estimate of market value.
<b>Stocks and work in progress</b>	These are valued at the lower of cost or market value.

## 2. ANALYSIS OF INCOME AND ENDOWMENTS

Analysis		2023 (£)	2022 (£)
<b>Donations and Legacies</b>	Restricted income	1,110,711	822,199
	Unrestricted income	73,928	89,676
		<b>1,184,639</b>	<b>911,875</b>
<b>Other trading activities</b>		-	-
<b>Income from investments</b>	Bank interest	3,111	76
<b>Other income</b>		5,000	-
<b>Total income and endowments</b>		<b>1,192,750</b>	<b>911,951</b>

### 3. ANALYSIS OF RESOURCES EXPENDED

Analysis		2023 (£)	2022 (£)
<b>Costs of generating voluntary income</b>	Staff costs	37,299	44,057
	Support costs	10,206	12,543
		<b>47,505</b>	<b>56,600</b>
<b>Charitable activities</b>	Staff costs	149,196	102,800
	Support costs	40,823	29,266
	Direct project costs	818,439	583,305
		<b>1,008,458</b>	<b>715,371</b>
<b>Governance costs</b>	Independent examiner's fee	12,840	1,320
	Accounting advice & payroll services	1,950	4,655
	Trustees' expenses	-	-
	Trustee meeting	-	-
		<b>14,790</b>	<b>5,975</b>
<b>Total</b>		<b>1,070,753</b>	<b>777,946</b>

### 4. TANGIBLE FIXED ASSETS

	Freehold land and buildings (£)	Other land and buildings (£)	Plant, machinery and motor vehicles (£)	Fixtures, fittings and equipment (£)	Total (£)
<b>Cost</b>					
At 1 January 2023	-	-	14,608	-	14,608
Additions	-	-	31,594	-	31,594
Disposals	-	-	-	-	-
At 31 December 2023	-	-	46,202	-	46,202
<b>Depreciation</b>					
At 1 January 2023	-	-	6,676	-	6,676
Charge for the year	-	-	10,019	-	10,019
Disposals	-	-	-	-	-
At 31 December 2023	-	-	16,659	-	16,659
<b>Net Book Value</b>					
At 31 December 2023	-	-	29,507	-	29,507
At 1 January 2023	-	-	39,526	-	39,526

## 5. DEBTORS AND PREPAYMENTS

Analysis of debtors	Amounts falling due within one year (£)		Amounts falling due after more than one year (£)	
	2023	2022	2023	2022
Trade debtors	-	-	-	-
Amounts due from subsidiary and associated undertakings	-	13,651	-	-
Other debtors	-	-	-	-
Prepayments and accrued income	25,519	86,823	-	-
<b>Total</b>	<b>25,519</b>	<b>100,474</b>	<b>-</b>	<b>-</b>

## 6. CREDITORS AND ACCRUALS

Analysis of creditors	Amounts falling due within one year (£)		Amounts falling due after more than one year (£)	
	2023	2022	2023	2022
Loans and overdrafts	-	-	-	-
Trade creditors	-	-	-	-
Amounts due to subsidiary and associated undertakings	-	-	-	-
Other creditors	7,014	3,797	-	-
Accruals and deferred income	31,586	33,548	-	-
<b>Total</b>	<b>38,600</b>	<b>37,345</b>	<b>-</b>	<b>-</b>

## 7. RESTRICTED FUNDS

Fund Name	Purpose and Restrictions
<b>Skin Cancer Prevention</b>	Skin cancer prevention services for people with albinism in Tanzania and Malawi
<b>Research</b>	Research into access to health for people with albinism in Tanzania
<b>Awareness Raising</b>	Creating and promoting positive imagery of people with albinism in Africa to raise awareness
<b>Vision and Education Programme</b>	Low Vision services and promotion of education for people with albinism in Tanzania and Malawi
<b>Umoja Children Centre</b>	Building of a centre for learning and healing for children with albinism in Tanzania
<b>Malawi Operations</b>	Operational overheads for Standing Voice's team based in Lilongwe
<b>Welfare Programme</b>	Psychosocial support and material assistance for survivors of abuse

### Movement of major funds:

Fund names	Fund balances brought forward 1 January 2023 (£)	Restricted Incoming resources (£)	Restricted outgoing resources (£)	Transfers (£)	Gains and losses (£)	Fund balances carried forward 31 December 2023 (£)
Skin Cancer Prevention Research	1,145	473,111	457,368	-	-	16,888
Awareness Raising	-	-	-	-	-	-
Vision and Education Programme	50,239	-	-	-	-	50,239
Umoja Children's Centre	8,801	104,291	116,685	-	-	(3,593)
Malawi Operations	208,508	27,184	97,601	-	-	138,091
Welfare Programme	567	20,000	19,895	-	-	672
Core Costs	771	109,305	54,205	-	-	55,871
	107,081	376,820	257,411	-	-	226,490
<b>Total Restricted Funds</b>	<b>377,112</b>	<b>1,110,711</b>	<b>1,003,165</b>	<b>-</b>	<b>-</b>	<b>484,658</b>

## 8. UNITED NATIONS VOLUNTARY FUND FOR VICTIMS OF TORTURE

Grant income	2023 (£)
P-1187-DA-22	40,196
Expenditure	2023 (£)
Salaries	10,770
Beneficiary support and training	27,162
International travel	-
National travel	1,139
Contribution to the Independent Examination of the charity's accounts	1,125
<b>Total amount (£)</b>	<b>40,196</b>

## 9. DETAILS OF CERTAIN ITEMS OF EXPENDITURE

Trustee expenses	2023 (£)	2022 (£)
Number of trustees who were paid expenses	-	1
Nature of the expenses	-	Bill payments
<b>Total amount paid (£)</b>	<b>-</b>	<b>-</b>

Fees for examination of the accounts	2023 (£)	2022 (£)
Independent examiner's or auditor's fees for reporting on the accounts	12,840	1,320
Other fees (for example: advice, consultancy, accountancy services) paid to the independent examiner or auditor	1,950	3,696

### Support costs:

Support Costs Type	Fundraising activity (£)	Charitable Activity (£)	Governance Activity (£)	Total Cost (£)
Building costs	5,012	20,047	-	25,059
Communications	1,213	4,851	-	6,064
Legal & professional	798	3,193	-	3,992
Other costs	964	3,855	-	4,819
Financial costs	215	861	-	1,076
Depreciation	2,004	8,016	-	10,020
<b>Total amount (£)</b>	<b>10,206</b>	<b>40,823</b>	<b>-</b>	<b>51,029</b>

## 10. GRANT-MAKING

Grants to individuals/institutions Purpose for which grants made	31 Dec 2023 Total amount (£)	31 Dec 2022 Total amount (£)
Health services / Skin cancer prevention treatments and manufacturing of sunscreen	-	6,000
<b>Total amount (£)</b>	<b>-</b>	<b>6,000</b>

*There were no support costs associated with the charity's grant-making.*

## 11. STAFF COSTS

Staff costs	2023 (£)	2022 (£)
Gross wages, salaries and benefits in kind	165,357	136,148
Employer's National Insurance costs	17,275	7,513
Pension costs	3,863	3,196
<b>Total staff costs</b>	<b>186,495</b>	<b>146,857</b>

Average number of full-time equivalent employees in the year	2023	2022
<i>The parts of the charity in which the employees work:</i>		
Fundraising	2	2
Charitable activities	3	3
Governance	1	1
Other	-	-
<b>Total</b>	<b>6</b>	<b>6</b>

## 12. TRANSACTIONS WITH RELATED PARTIES

Name of trustee or connected party	Legal authority (e.g. order, governing document)	Amounts paid or benefit value	
		2023 (£)	2022 (£)
Harry Freeland	Governing document	56,667	45,000

*There are no amounts owing to or from the charity's trustees or other related parties by the charity at the year end. All transactions undertaken by (or on behalf of) the charity in which a trustee or related party has a material interest have been disclosed in the Notes to the Accounts.*







**STANDING VOICE**

England & Wales - Charity number 1151250

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# Accounts

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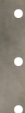


# Trustees' Annual Report and Accounts

## 2022



Registered with  
**FUNDRAISING  
REGULATOR**



Registered charity  
No.1151250

## FOREWORD

I want to begin by thanking all of our partners, supporters, volunteers and staff teams for your unwavering commitment to Standing Voice this year. Due to your continued support and generosity our work has been able to go from strength to strength in 2022.

As the world continues to recover from the Covid-19 pandemic, and new global uncertainties appear, Standing Voice remains resolute in its mission to protect and empower people with albinism throughout Tanzania, Malawi and beyond.

During 2022 our income has seen positive growth from the previous year and our financial stability has made a strong recovery following the challenging period of the pandemic. As a result, this year we were able to expand our life saving work to new areas of Tanzania and Malawi. This included introducing new initiatives to support the most vulnerable and at-risk people with albinism in these countries.

This year we continued our focus of training frontline workers, civil society groups and human rights defenders so they are better prepared to respond to the needs of people with albinism. Our Skin Cancer Prevention Programme is now providing life saving dermatological healthcare and education to 8,076 people with albinism in 150 hospitals and health centres across Tanzania and Malawi. Meanwhile our Vision and Education Programme has also accelerated its expansion, with specialist eye care now accessible to 2,903 people with albinism in Tanzania.

To continue forging a future where children with albinism are free to realise their full potential, our team partnered with schools across Tanzania to deliver a teacher training programme. Through this programme 167 teachers were equipped with the skills and knowledge to meet the needs of students with albinism, while thousands of students and community members have been reached with awareness raising and education.

It's a tragic reality that people with albinism and their families continue to be targeted with violent abuse throughout Tanzania and Malawi, with a spate of unimaginable human rights violations reported in the last few weeks alone. As well as applying pressure to governments to take action, and raising awareness of these atrocities internationally, we are working hard to provide direct support to survivors so they can recover from trauma and rebuild their lives. Our First Response Team is at the forefront of this support, providing emergency support and a package of tailored assistance to people with albinism who have been victims to abuse including; urgent physical and mental healthcare, housing and home security measures, micro-finance and livelihood support, access to justice and facilitation of ongoing psychosocial support and counselling. We are also partnering with community organisations such as the Mothers' Albinism Action Group: a fierce collective of advocates who are providing peer counselling to other mothers, children and families across their communities in Tanzania.

Our devastation at the ongoing assault on the human rights of people with albinism is outweighed only by our determination to bring about positive change. We remain more committed than ever to building a world where the rights of people with albinism are universally upheld, and respected, and all forms of abuse against this group are ended.

Thank you to every single person and organisation who have contributed towards realising our objectives in 2022. Without you, our work would not be possible.

*Presented by*

A handwritten signature in black ink that reads 'Sabine Zettler'.

*Sabine Zettler*  
*Chair of the Board of Trustees*  
28/01/2023

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## 1. LEGAL AND ADMINISTRATIVE INFORMATION

<i>Charity Name</i>	Standing Voice (UK)
<i>Charity No.</i>	No. 1151250 Charitable Incorporated Organisation (CIO)
<i>Administrative offices</i>	<p>Standing Voice UK          Unit 34b          Regent Studios          8 Andrews Road          London          E8 4QN</p> <p>Standing Voice Tanzania          P.O. BOX 1902          Isamilo, Mwanza          Tanzania</p> <p>Standing Voice Malawi          Area 14          Plot No.63          Lilongwe</p>
<i>Registered Addresses</i>	<p>49 Newick Road          London          E5 0RP</p> <p>P.O. BOX 180          Ukerewe Island, Mwanza          Tanzania</p> <p>Area 14          Plot No.63          Lilongwe</p>
<i>UK Board of Trustees</i>	Sabine Zetteler (Chair) Gurmeet Kaur (Treasurer) Innocentia Magijima Harry Freeland
<i>Malawi Board of Trustees</i>	Grace Malera Tadala Peggy Chinkwezule Jonathan Beale
<i>Tanzania Board of Trustees</i>	Katwale Bunoge Magaga Ally Possi Sister Martha Mganga
<i>UK Administration</i>	Harry Freeland, Jonathan Beale Sam Clarke, Emily Spence, Kathrin Scholler, Giovanna Giuriolo, Nofal Pasha. Supported by a growing team of dedicated volunteers

## 2. REPORT OF THE TRUSTEES

### 2.1 Constitution

Standing Voice (UK) was originally constituted under a Foundation Constitution that came into effect on 14th March 2013, on which date Standing Voice became registered as a Charitable Incorporated Organisation (CIO). The trustees are the only members of the CIO. If the CIO is wound up the members have no liability to contribute to its assets and no personal responsibility for settling its debts or liabilities.

### 2.2 Board of Trustees

Trustees are appointed by existing trustees through an electoral process. There may be no fewer than three trustees at any one time on the Board of Trustees. There are four at present, and we aim to expand the Board further during 2023.

Standing Voice trustees hold quarterly board meetings. The board also addresses governance matters as and when necessary, through e-mail or other means as necessary.

Decisions are made either at a meeting of the charity trustees, by resolution in writing or electronic form and agreed upon by all of the charity trustees. Agreements may comprise either a single document, or several documents containing the text of the resolution in like form to each of which one or more charity trustees has signified their agreement.

No decision shall be made at a trustee meeting unless a quorum is present at the time the decision is taken. The quorum is two charity trustees, or the number nearest to one third of the total number of charity trustees, whichever is greater, or such larger number as the charity trustees may decide from time to time.

In selecting trustees, consideration is given to the overall breadth of knowledge and experience required of the Board of Trustees. Candidates are typically interviewed by at least two existing trustees and nominations are then presented for approval to the board. Successful candidates, once appointed, receive appropriate documentation about the roles and responsibilities of being a Standing Voice trustee.

Standing Voice has three international boards: Standing Voice UK (4 members), Standing Voice Tanzania (4 members) and Standing Voice Malawi (3 members).

### 2.3 Advisory Board

The Standing Voice Board of Trustees is supported by an Advisory Board made up of 9 experts from 7 countries (Malawi, Tanzania, Togo, USA, UK, France and Ireland). This includes a wide range of expertise in the fields of public health, dermatology, ophthalmology, education, trauma recovery, genetics, general medicine and surgery, and in-depth knowledge on albinism.

The Advisory Board provides expert guidance to the UK Board of Trustees and staff management team, by advising on strategy, and informing the design and implementation of our programmes. The Advisory Board also works closely with Standing Voice's wider staff teams, with a primary focus on developing resources and training manuals, leading the delivery of clinical and surgical training, conducting research and publication, and identifying funding opportunities.

Our warmest thanks go to our Advisory Board; Our current Chair of the Board Dr Andrew Sharp, and members; Professor Daudi Mavura, Dr Kelvin Maponda, Professor Melissa Levin, Dr Mark Wheeler, Professor Bayaki Saka, Dr Patricia Lund, Professor Charlotte Baker and Mark Fish.

## 2.4 Organisational Structure

The UK Board of Trustees manages the governance affairs of the charity on a voluntary basis and meets as necessary for this purpose, at least once a quarter. Standing Voice's Malawi and Tanzania offices report to Standing Voice UK. Therefore, the UK Board has primary governance responsibility for all Standing Voice operations. UK Trustees represent a range of fields and expertise including international development, human rights, financial management, public relations, media and the arts.

The UK Executive Management team oversees all high level strategic decisions across Standing Voice's offices. The UK Programmes and Financial Management Team ensures that all implementation is delivered in line with organisational strategy and to the requirements of Standing Voice's funders, as well as internal and statutory financial regulations. Our UK Communications and Fundraising Team oversees the procurement of funding to sustain and grow our work, and ensure the charity maintains a high level of visibility around the world.

Our registered offices in Malawi and Tanzania are each governed by its own Board of Trustees which oversees all governance matters within the context of local standards, regulations and protocols. Standing Voice maintains a breadth of expertise on each of our local Boards which include human rights and employment lawyers, human rights advocates, management experts and representatives of National Human Rights Institutions. Staff team management in each of the Standing Voice country teams is handled by the Executive Director of the Malawi and Tanzania office respectively.

Harry Freeland is Executive Director of Standing Voice UK (since April 2014) and remains on the UK Board of Trustees. During the report period the charity had 6 paid staff members in the UK supported by a committed team of volunteers. Our global team comprises an additional 19 paid staff members based in Tanzania and 5 based in Malawi, as well as international consultants.

People with albinism and their families are key decision-makers embedded at every level of Standing Voice. As trustees and senior leaders across our UK, Tanzania and Malawi offices, people with albinism and their families are actively engaged in governance, programme design and fundraising, building and shaping a culture of accountability grounded in, and responsive to, the lived experience of our service users.

## 2.5 Contributions of Volunteers

Standing Voice continues to work closely with skilled volunteers from a variety of professional and academic backgrounds who are committed to ending human rights abuses against people with albinism.

Our programmes are supported by a pool of local and international expert volunteer researchers, professors, ophthalmologists, dermatologists, geneticists and performance artists who continue to complement the development and expansion of our work through the provision of research, resource development, training, and ongoing mentorship during the reporting period.

Our volunteer engagement has resulted in a unique pool of expertise on albinism supporting Standing Voice's global operations. We have formalised this provision of expertise through the establishment of our advisory board, which plays a vital role in supporting our country Boards of Trustees and staff teams.

We are extremely grateful to all the volunteers who continued to inform and shape our life-saving programmes this year.

## 2.6 Our Purpose and Objectives

Standing Voice is an international NGO working in Tanzania and Malawi, with its headquarters in the United Kingdom. Standing Voice's primary objective is to improve the quality of life of people with albinism in Africa.

The objectives of the CIO are:

- I. the advancement of education;
- II. the advancement of mental and physical health and the saving of lives;
- III. the relief of poverty and the improvement of the conditions of life in socially and economically disadvantaged communities;
- IV. the promotion of human rights and the promotion of equality and diversity, in particular but without limitation so as to relieve the needs of people who are socially excluded by assisting them to integrate into society.

For the purposes of the above:

I. "human rights" means human rights as defined in the Universal Declaration of Human Rights and subsequent United Nations conventions and declarations and will be promoted in particular by education about human rights and promoting respect for human rights;

II. people who are "socially excluded" means people who are excluded from society, or parts of society, as a result of one or more of the following factors: financial hardship; youth or old age; ill health (physical or mental); disability or medical condition; discrimination on the grounds of sex, race, ethnic origin, religion, colour, creed or sexuality; poor education or skills attainment.

Standing Voice exists as a catalyst to amplify the voices of others. We aim to empower the people we work with to be the agents of change in their own lives, to build resilience and be healthy and self-sufficient. We currently focus on promoting the social inclusion of people with albinism in Tanzania and Malawi, whilst building the capacity of our partners in other countries in the region. Our team has over 17 years' experience working with this group and has pioneered innovative models of working that have a proven record of replication and scalability.

People with albinism are commonly the victims of social exclusion in Sub-Saharan Africa, which has led to witchcraft-fuelled murder and marginalisation from health and education services. Our work with this group centres around several programmatic areas: Skin Cancer Prevention, Vision and Education, Trauma Recovery, Economic Empowerment and Advocacy. Through our core programmes our support is holistic and comprehensive to reflect the complex needs of people with albinism in their local context. We achieve our objectives by collaborating with a network of local stakeholders (such as government bodies, local community groups and NGOs). All of our initiatives promote the social inclusion of people with albinism by:

- I. Advancing understanding and knowledge about albinism in wider society
- II. Advocating for progressive state action
- III. Developing the skills and expertise of both people with albinism and wider community members
- IV. Increasing the positive impact of local service providers
- V. Promoting the positive impact of local non-governmental stakeholders (civil society)

The trustees of Standing Voice declare that they have had regard to both the Charity Commission guidance on public benefit and section 17(5) of the Charities Act 2011 on public benefit in carrying out their duties to achieve the charity's objectives.

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### 3. PRINCIPAL ACTIVITIES

In 2022 we delivered programmes in Health, Education, Community development, Livelihoods and trauma recovery, reaching thousands of people with albinism across Tanzania and Malawi.

Through all these interventions we're now reaching 8,817 people with albinism with essential services.



## 4. SKN CANCER PREVENTION PROGRAMME

### 4.1 Reach and Growth

To confront the skin cancer crisis faced by people with albinism in Africa, Standing Voice launched its Skin Cancer Prevention Programme (SCPP). This growing network of dermatology clinics is reaching over 8,000 people with albinism throughout Tanzania and Malawi. Declared best practice by the United Nations in 2017, this programme is delivered in partnership with the Governments of Tanzania and Malawi, and is supported by hundreds of health professionals and civil society actors. Through the support of the Pierre Fabre Foundation we have been able to expand the SCPP at scale, transforming it into the largest skin cancer prevention programme for people with albinism existing in Africa today.

Each clinic provides health education, skin examination, cryotherapy, and referral for surgery if required. Patients also receive sunglasses, locally made sun hats and a fresh supply of sunscreen at every clinic. Our objective is to support governments and civil society to build national programmes of skin cancer prevention that reach every region and serve the total population of people with albinism.

During 2022 we have expanded the SCPP into 2 new regions of Tanzania and 5 new districts of Malawi. We conducted mapping exercises and engagement meetings with government and civil society to ensure the full mobilisation of people with albinism and their duty bearers in the delivery of the SCPP, and we have continued to deliver training to health professionals and community advocates, who lead the programme's expansion across both countries. We have seen significant growth in the number of patients enrolled across all programme areas, and we are on target for the SCPP to achieve national coverage of both Tanzania and Malawi by the end of 2027.

Indicator	Tanzania			Malawi		
	Target	Achieved	Difference	Target	Achieved	Difference
<b>Number of regions/districts covered by SCPP</b>	17	17	0	6	12	6
<b>Number of clinics delivered during reporting period</b>	170	203	33	60	84	24
<b>Total number of patients registered in the database</b>	4,590	6,270	1,680	1,200	1,806	606
<b>Patients seen in this period</b>	1,200	4,651	N/A	1,200	1,521	N/A
<b>New patients seen in this period</b>	540	1,337	797	300	847	547

By the end of 2022, the SCPP had exceeded or met all targets regarding patient reach and geographical coverage. The programme had registered 8,076 patients across Tanzania and Malawi, surpassing our combined target of 5,790 patients for both countries by a margin of 28.3%. This included 6,270 patients in Tanzania and 1,806 patients in Malawi.

17 regions of Tanzania were reached during this reporting period (meeting our target for the end of 2022), while 12 districts of Malawi were reached (surpassing our target of 7 districts). This means that today the SCPP is operational in 55% of all regions in Tanzania (17 of 31), and 43% coverage of all districts in Malawi (12 of 28). Clinics are now active in 150 Govt hospitals and health centres across both countries. 103 of these facilities are in Tanzania, and 47 are in Malawi. A total of 287 clinics were delivered across both countries during the reporting period. 203 of these were in Tanzania and 84 in Malawi. Since July 2021 and the start of the phase II partnership with the Foundation Pierre Fabre, 363 clinics have been delivered across Tanzania and Malawi.

Across the entire year we welcomed a total of 2,184 new patients across both countries, reflecting a combined annual growth rate of 27%. In Tanzania, there were 1,337 new patients registered in 2022 (a growth rate of 27.1% from 2021). In Malawi, we saw 847 new patients in 2022 (a growth rate of 88.3% from 2021). This fast rate of patient growth in Malawi was down to districts the SCPP operates in nearly doubling from 7 to 12.

## 4.2 Demographic Breakdown

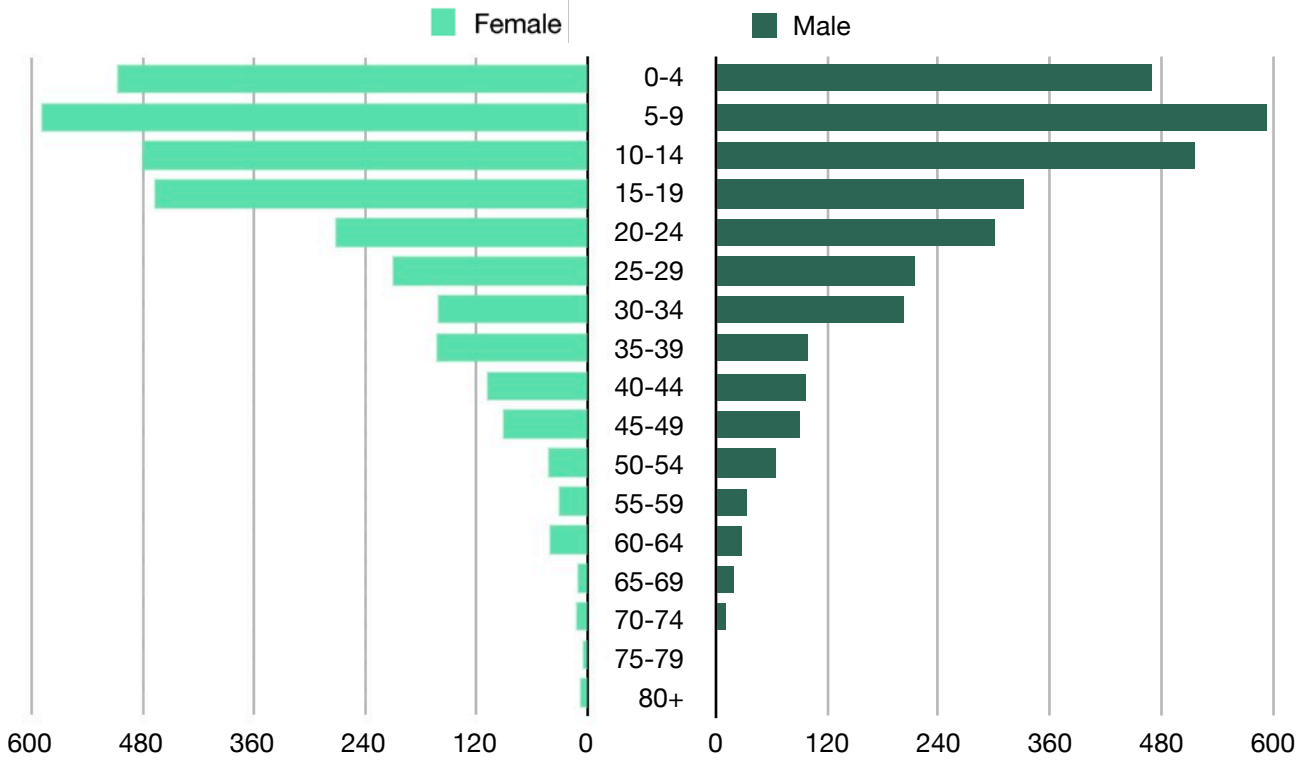
	Tanzania		Malawi	
	Number	%	Number	%
<b>Total registered patients</b>	6,270	N/A	1,806	N/A
<b>Female</b>	3,198	51.1%	909	50.4%
<b>Male</b>	3,072	48.9%	897	49.6%
<b>Average age</b>	19		17	
<b>0-9</b>	2,159	30.3%	639	30.4%
<b>10-19</b>	1,792	31.0%	548	32.3%
<b>20-29</b>	996	16.7%	304	18.0%
<b>30-39</b>	621	10.3%	169	10.4%
<b>40-49</b>	388	6.4%	87	4.6%
<b>&gt;50</b>	309	5.3%	52	4.3%
<b>Blank ages</b>	5	0.1%	7	0.4%

We are encouraged to see continued gender parity in our patient population, with women and men respectively comprising 51.1% and 48.9% of our patients in Tanzania, and 50.4% and 49.6% of our patients in Malawi. Younger age brackets continue to dominate our patient population in a manner that is consistent with the age distribution of the general population in both Tanzania and Malawi. In Tanzania, our average patient age is 19 and 63.0% of all registered patients are aged 19 or below; in Malawi, the average age is 17 and 65.7% of all registered patients are aged 19 or below. Across both countries 5,138 people (or 63.6%) of all registered patients are under the age of 19, and 79.7% of all registered patients are under the age of 30. Compared with 20.2% over 30, and just 4.5% over the age of 50. The population pyramids below demonstrate particularly strong mobilisation of patients aged 5-19 in both Tanzania and Malawi.

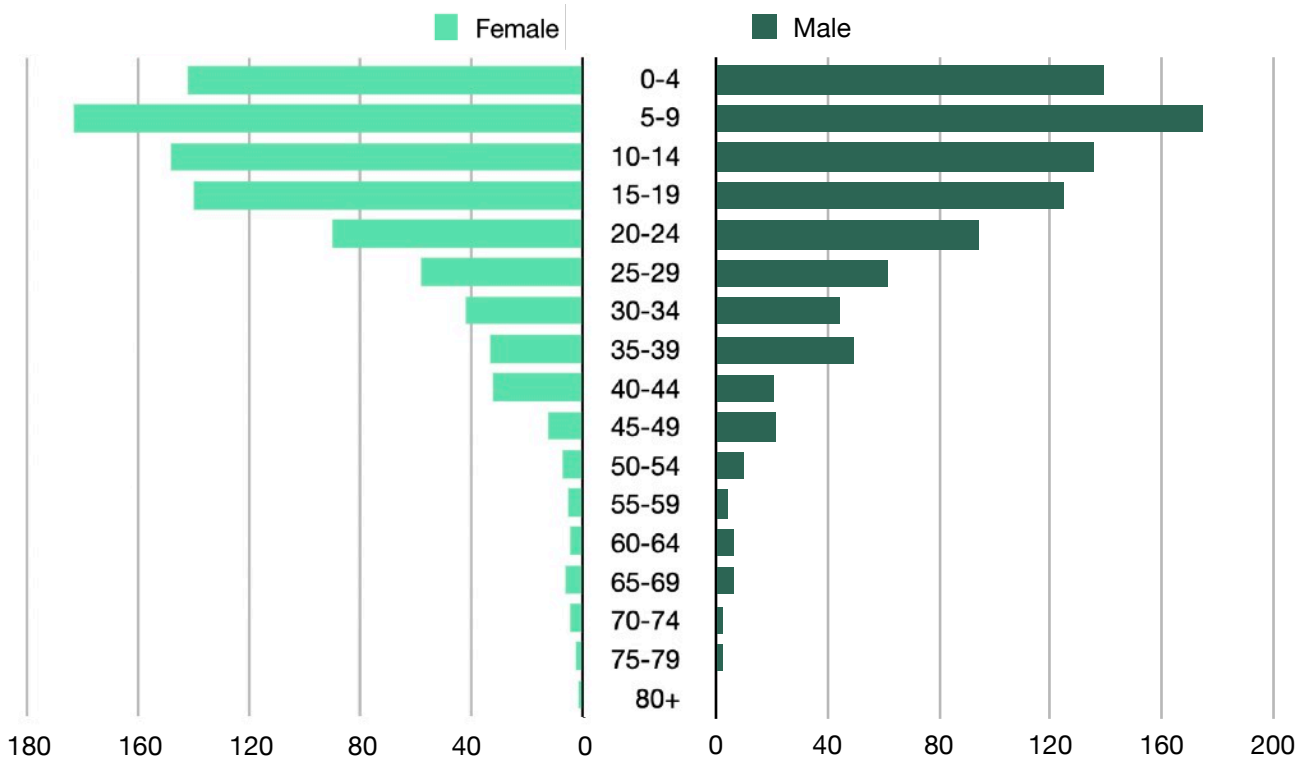


The population pyramids below demonstrate particularly strong mobilisation of patients aged 5-19 in both Tanzania and Malawi.

**Distribution of Registered Patients in Tanzania**

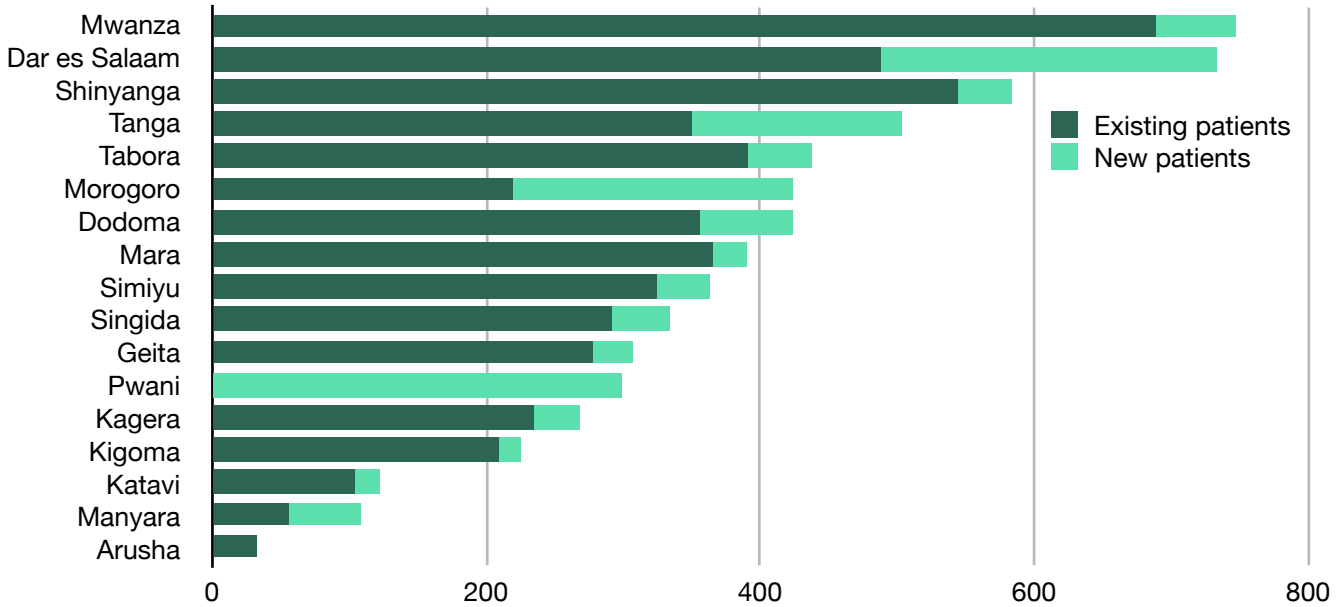


**Distribution of Registered Patients in Malawi**

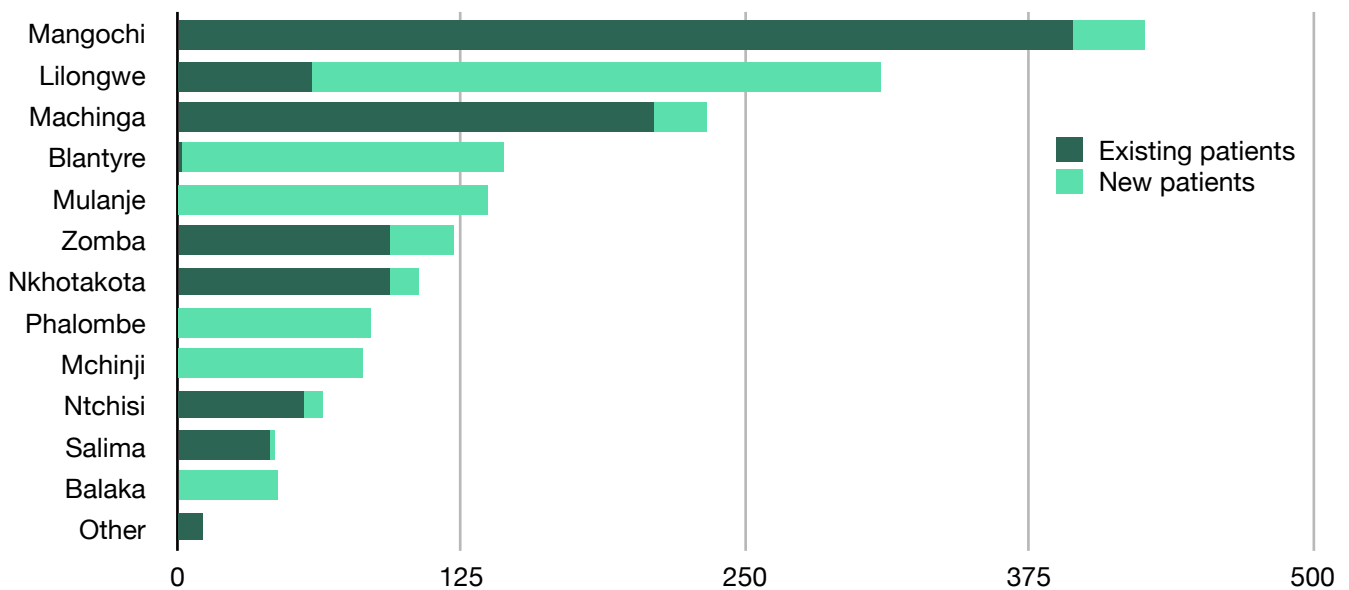


### 4.3 Geographic Breakdown

Annually, we saw a 28.3% increase in registered male patients and a 26.0% increase in registered female patients in Tanzania. Our fastest-growing regions were Morogoro (92.7%), Dar es Salaam (50.2%) and Tanga (44.0%), while our slowest-growing were Shinyanga (7.0%), Mara (7.1%), Kigoma (7.1%) and Mwanza (8.4%) which are also the regions where the SCPP has been operating longest.<sup>1</sup>



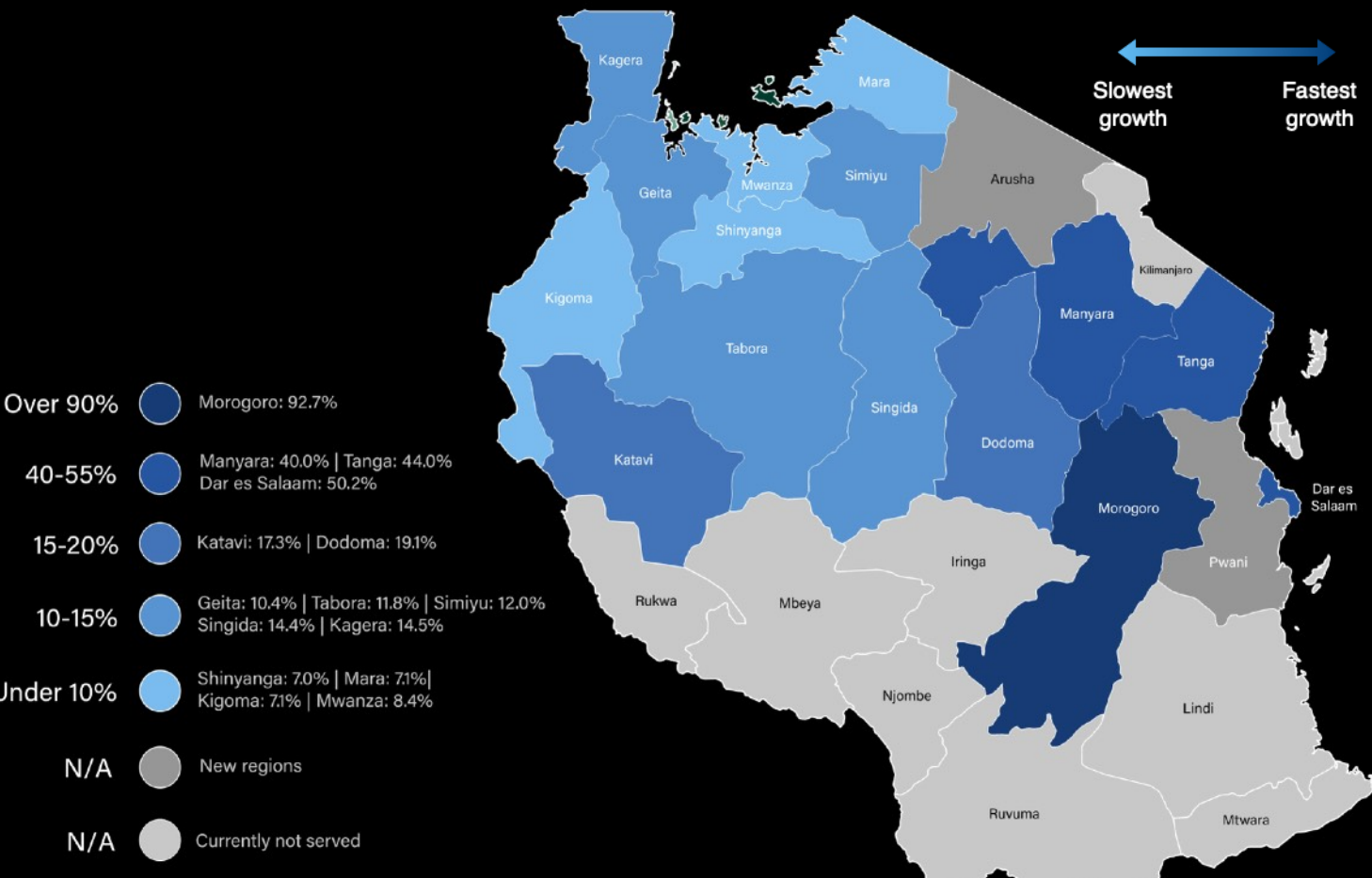
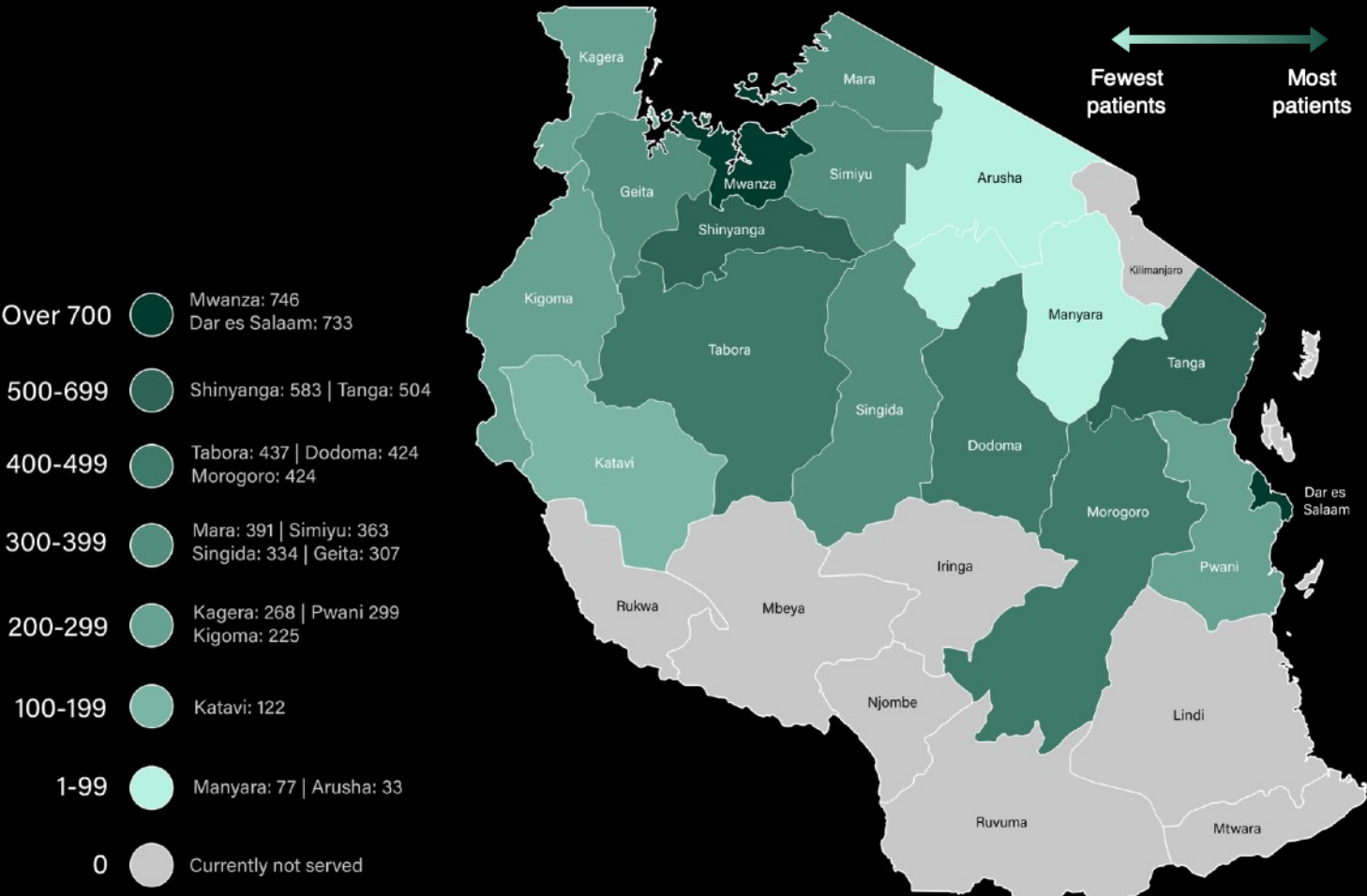
Annually, we saw a 90.0% increase in registered male patients and a 86.7% increase in registered female patients in Malawi. The fast rate of patient growth in Malawi was due to the number of districts the SCPP operates in almost doubling from 7 to 12. By far our fastest-growing district was Lilongwe (423.7%),<sup>2</sup> followed by Zomba (31.0%). Our longest running districts in Malawi; Salima (4.90%), Mangochi (8.1%) and Machinga (11.0%) saw the slowest patient growth.<sup>3</sup>



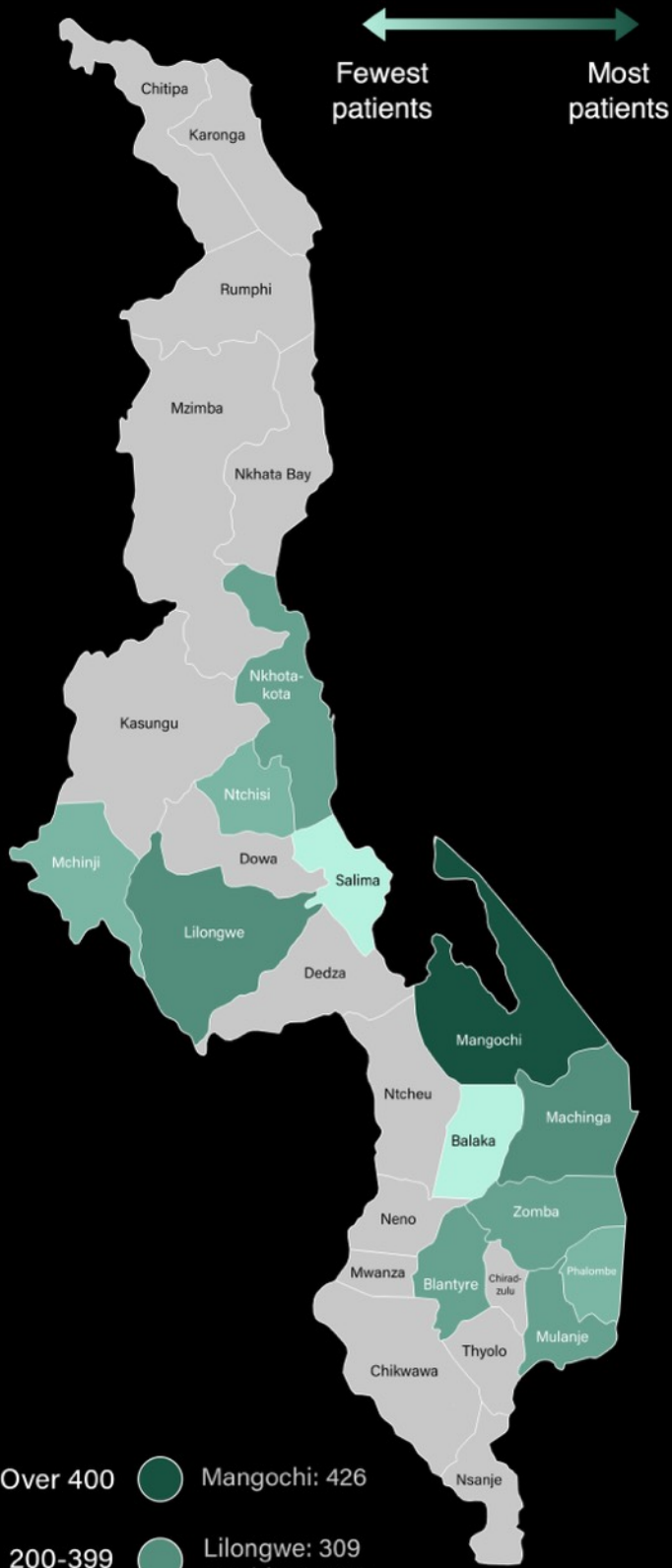
1. Growth is N/A for Pwani (which was entirely new region in 2022); and for Arusha, which has a small number of historic patients, but remains a training ground for DVOs studying at the RDTC.

2. The SCPP launched in Lilongwe at the end of 2021, however the majority of clinic sites were opened during 2022 which resulted in substantial growth during the reporting period. For this reason it is counted as a new region in the Malawi growth maps on page 15. It is only possible to measure growth in registered patients for the 6 districts of Malawi where the SCPP was operating before and during this reporting period. Growth is N/A for Blantyre, Mulanje, Phalombe, Mchinji and Balaka (which were entirely new in 2022)

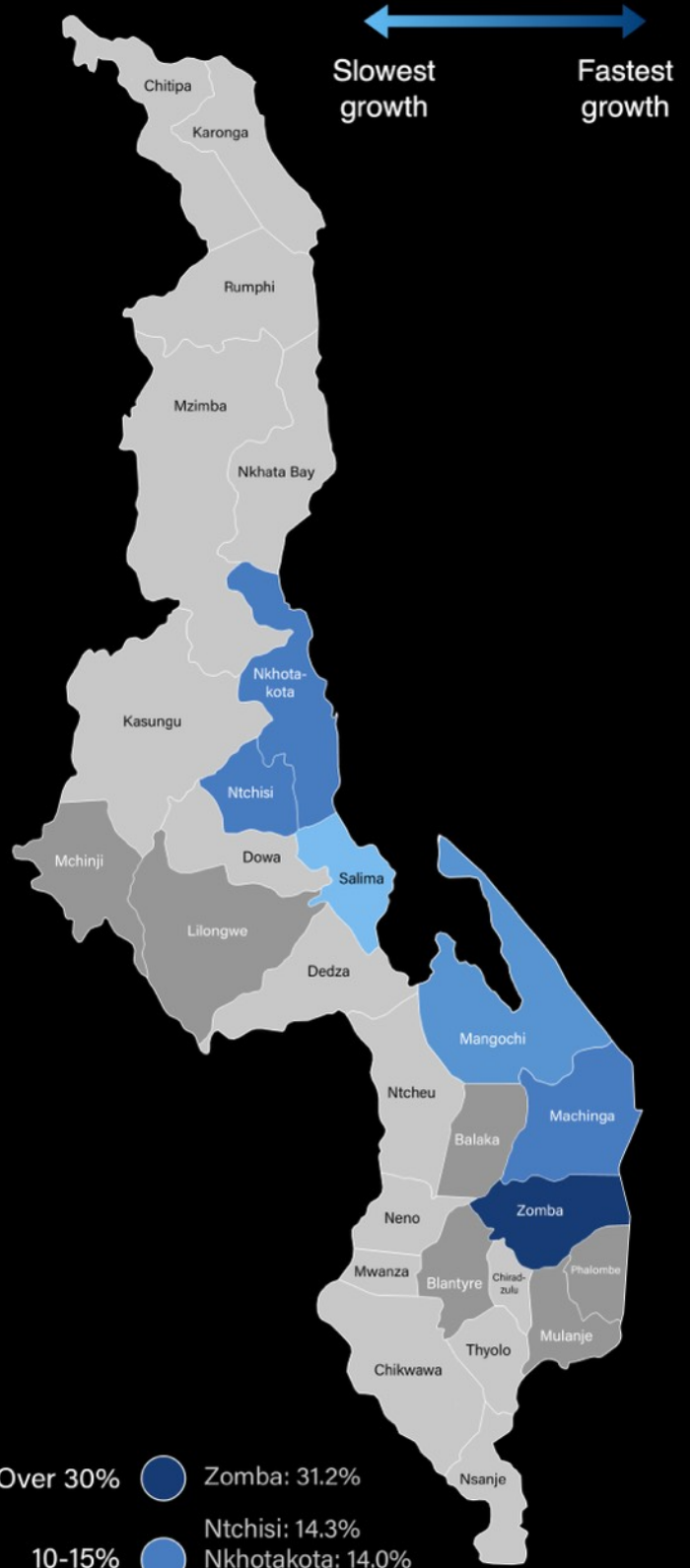
The top map indicates the distributional density of our registered patients in Tanzania: Mwanza has the most patients (746) while Arusha has the fewest (33). The bottom map indicates regional growth rates in registered patients: Morogoro is growing quickest (92.7%), while Shinyanga is growing slowest (7.0%).



The map on the left indicates the distributional density of our registered patients in Malawi: Mangochi has the most patients (426) while Salima has the fewest (43). The map on the right indicates district growth rates in registered patients: excluding Lilongwe<sup>2</sup> for the reasons explained in the footnote above, the quickest growth was in Zomba (31.2), while Salima is growing slowest (4.9%).



- Over 400 ● Mangochi: 426
- 200-399 ● Lilongwe: 309  
Machinga: 233
- 100-199 ● Blantyre: 144 | Mulanje: 137  
Zomba: 122 | Nkhotakota: 106
- 50-99 ● Phalombe: 85 | Mchinji: 82  
Ntchisi: 64
- 1-49 ● Balaka: 44 | Salima: 43
- 0 ● Currently not served



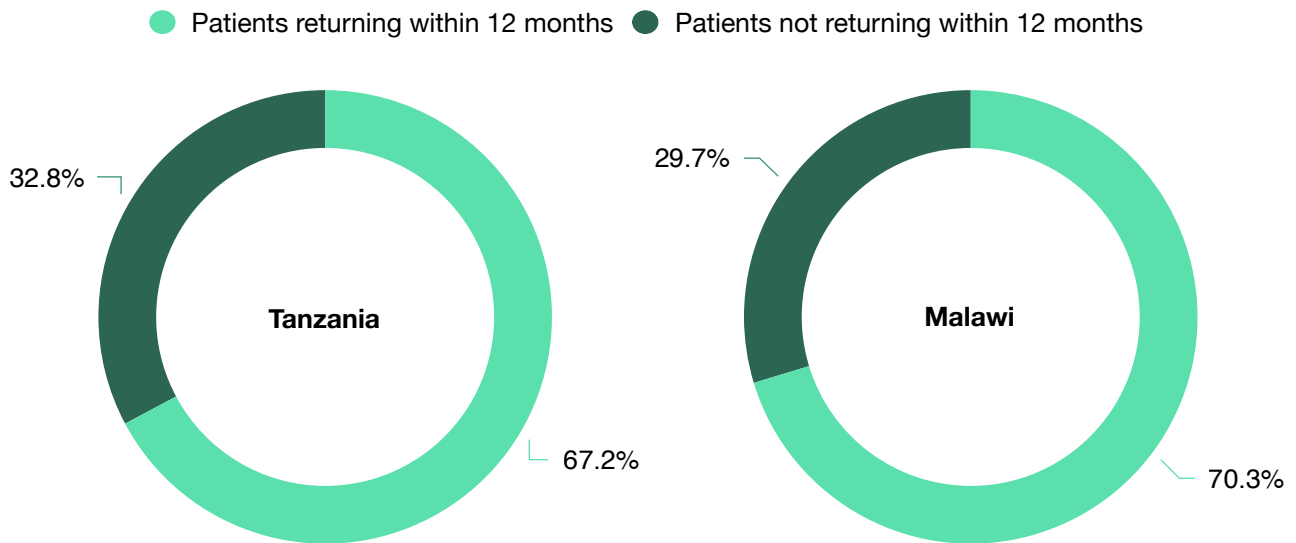
- Over 30% ● Zomba: 31.2%
- 10-15% ● Ntchisi: 14.3%  
Nkhotakota: 14.0%  
Machinga: 11.0%
- 5-10% ● Mangochi: 8.1%
- Under 5% ● Salima: 4.9%
- N/A ● New regions
- 0 ● Currently not served

## 4.4 Retention

In Tanzania, we saw 4,651 patients throughout 2022. Of these, 3,314 patients were returning within 12 months (representing an annual retention rate of 67.2%). In Malawi the picture was similar: in 2022 we saw 1,521 patients, of whom 674 were returning within 12 months (an annual retention rate of 70.3%). Across both countries in 2022 we saw 6,172 patients, of whom 3,988 were returning within 12 months (a combined annual retention rate of 67.7%).

Patient retention is a crucial indicator that helps us to measure the success of the SCPP in mobilising people with albinism and promoting their access to regular healthcare in order to prevent skin cancer. Retention is complex and can be challenging to guarantee (or even measure) for a number of reasons. Patient attendance can be undermined by a range of factors including:

- poverty and the cost or availability of transport
- employment commitments, especially for low-paid seasonal farmers
- childcare obligations
- poor weather conditions (monsoons can make roads impassable)
- fear of consultation or treatment
- reluctance to attend hospital through fear of forced vaccination for Covid-19 (a baseless rumour that has circulated powerfully in some districts of Malawi)
- patients already undergoing treatment
- patients not hearing about the service



Although universal retention is virtually impossible, we work hard to maximise accessibility and retention by identifying and alleviating barriers to attendance where we can. Retention of patients attending clinics remained high in 2022. Our electronic database is helping us to monitor retention more accurately. This year we have been looking carefully at how retention varies by location, age and gender to identify those populations at greatest risk of dropping out, so we can invest additional resources in mobilisation among these groups. We have begun introducing specific questions in CommCare to help us understand the facilitators and obstacles that have an impact on the ability of patients to attend SCPP clinics.

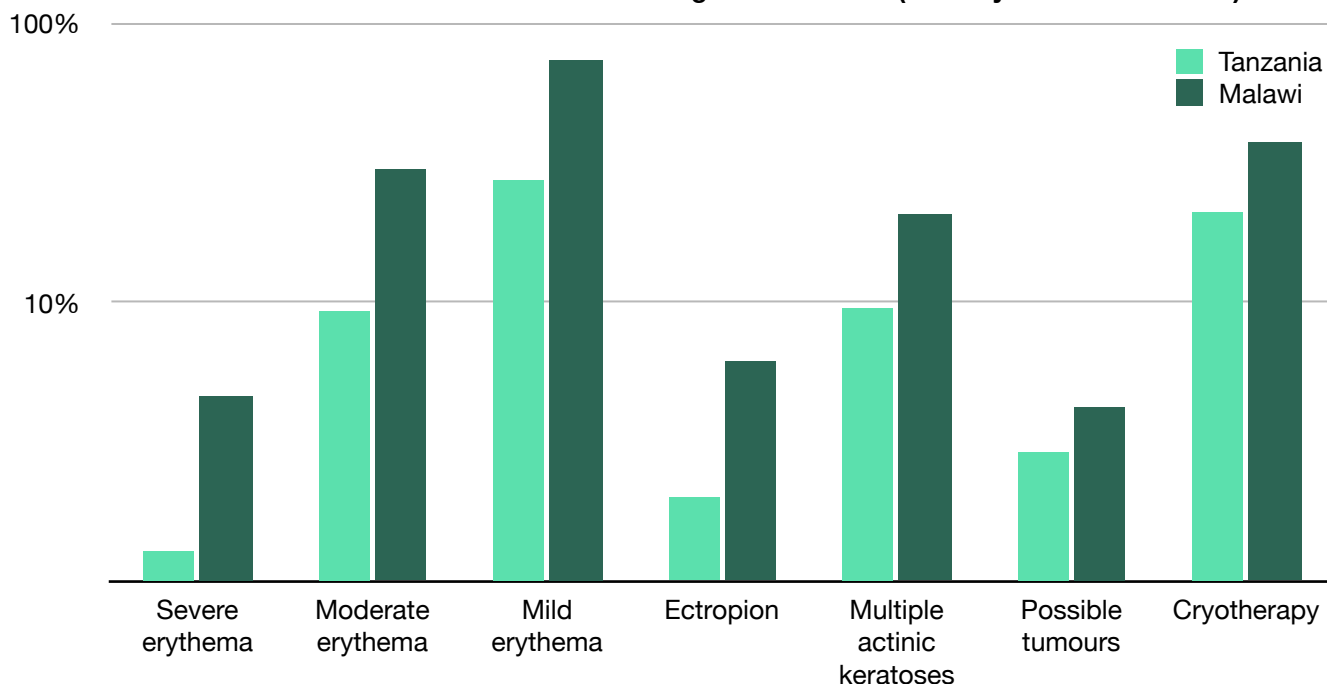
During the reporting period we introduced direct SMS communications with patients. This has not only strengthened and further diversified the methods we use to mobilise patients to clinics, but it also allows for easier follow up with patients if they are demonstrating usual patterns of attendance, or if they're high risk and require more careful tracking. For example we are able to identify patients who have not returned to clinics in 12 months or longer, and contact these individuals directly to understand the reasons for this dropout and encourage future attendance.

## 4.5 Screening and Medical Management

Indicator	Tanzania		Malawi		Total	
<b>Total patients seen</b>	4,651		1,521		6,172	
<b>Number of examinations</b>	7,528		2,314		9,842	
<b>Number of cryotherapy procedures<sup>7</sup></b>	3,458	46%	1,829	79%	5,287	
<b>Number of patients receiving cryotherapy</b>	986	21.2%	567	37.3%	1,553	19.2%
<b>Number patients referred for surgical procedures</b>	229	4.9%	118	7.8%	347	4.3%
<b>Number of examinations where patients present with...</b>						
Severe erythema	99	1.3%	107	4.6%	206	2.0%
Moderate erythema	699	9.3%	695	30.0%	1,394	14.1%
Mild erythema	2,085	27.7%	1,724	74.5%	3,810	38.7%
Ectropion	150	2.0%	141	6.1%	291	3.0%
Multiple AKs	726	9.6%	479	20.7%	1,205	12.2%
Possible tumours	220	2.9%	97	4.2%	317	3.2%

There were 9,842 skin examinations conducted in 2022. 7,528 of these were in Tanzania and 2,314 were in Malawi. Clinical data from this reporting period reveals a higher prevalence of skin conditions among patients in Malawi than in Tanzania. As a proportion of the total number of examinations delivered in each country, Malawi scored much higher in cryotherapy use 79%, compared to 46% in Tanzania. In addition multiple Actinic keratosis were found during 20.7% of all examinations conducted in Malawi, compared with 9.6% in Tanzania. Rates of erythema (sunburn) were three times more prevalent in Malawi than Tanzania across each of our three indicators used to record the severity of erythema on each patient; severe, moderate and mild. This is a trend we'd expect to see with the comparatively longer history of the SCPP in Tanzania, which has led to a greater baseline awareness and understanding of skin cancer and preventative measures among people with albinism. Due to the rapid expansion of the SCPP in Malawi during 2022 we enrolled a large number of new patients who had never before accessed Dermatology services. This provides additional reasons for the higher

**Prevalence of Clinical Conditions among Patients Seen (January – December 2022)**

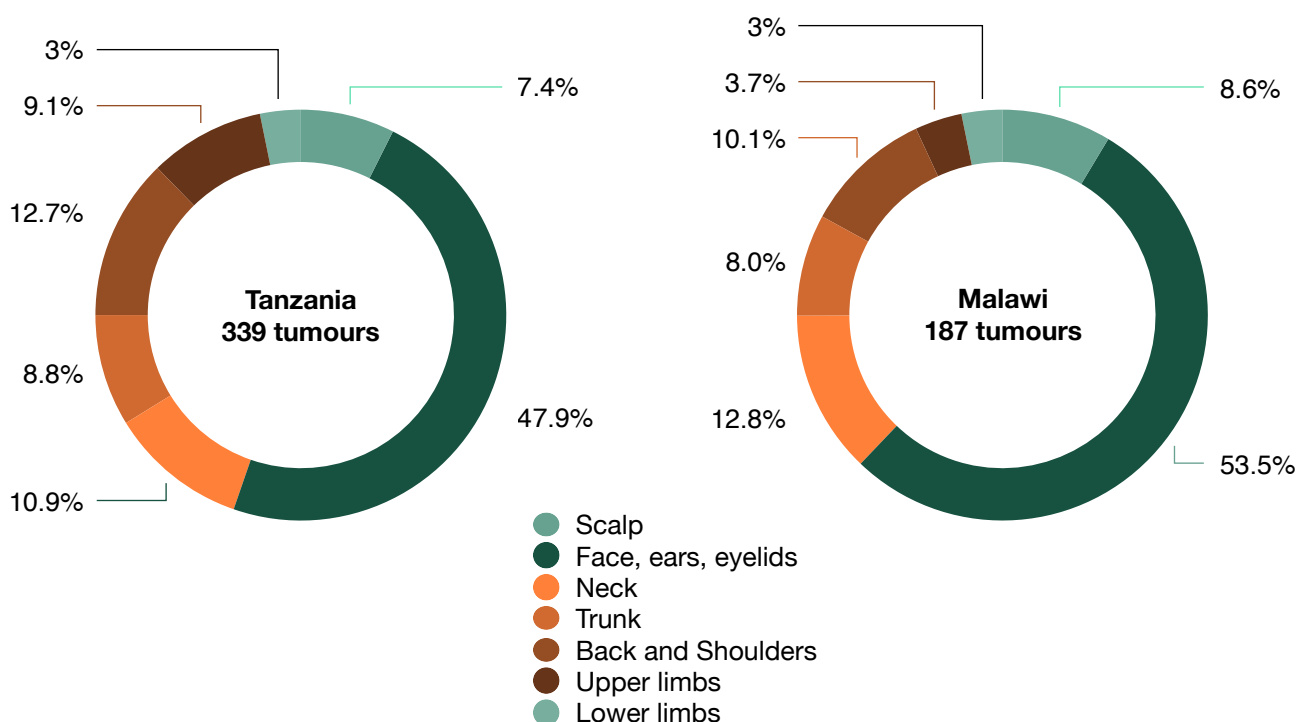


Provisional doctor's diagnosis during clinics 2022				
Indicator	Tanzania		Malawi	
<b>Possible tumours identified during clinics</b>	<b>339</b>		<b>187</b>	
<b>SCC</b>	168	49.6%	112	59.9%
<b>BCC</b>	142	41.9%	49	26.2%
<b>Other/unknown</b>	29	8.5%	26	13.9%
<b>Distribution of possible tumours by body part</b>	<b>339</b>		<b>187</b>	
<b>Scalp</b>	25	7.4%	16	8.6%
<b>Face, ears, eyelids</b>	162	47.9%	100	53.5%
<b>Neck</b>	37	10.9%	24	12.8%
<b>Trunk</b>	30	8.8%	15	8.0%
<b>Back and shoulders</b>	43	12.7%	19	10.1%
<b>Upper limbs</b>	31	9.1%	7	3.7%
<b>Lower limbs</b>	11	3.2%	6	3.2%

A total of 526 possible tumours were provisionally diagnosed during SPPP clinics. In Tanzania, doctors identified 339 possible tumours in 229 patients. 49.6% of tumours were identified as SCCs (down from 57.6% in 2021), 41.9% as BCCs (up from 37.4% in 2021), and 8.5% as other or unknown conditions (up from 5% in 2021). In Malawi, doctors found 187 possible tumours in 118 patients, with 59.9% diagnosed as SCCs (up from 22.0% in 2021), 26.2% as BCC (down from 51.2% in 2021), and 13.9% as other or unknown (down from 26.8% in 2021).

Distribution of tumours identified on body parts was similar in both countries. The body parts most affected in patients in both Tanzania and Malawi was the face, ears and eyelids, with 47.9% in Tanzania and 53.5% of all tumours identified being found on these three areas of the body.

**Distribution of tumours by body parts**



## 4.6 Referral Management

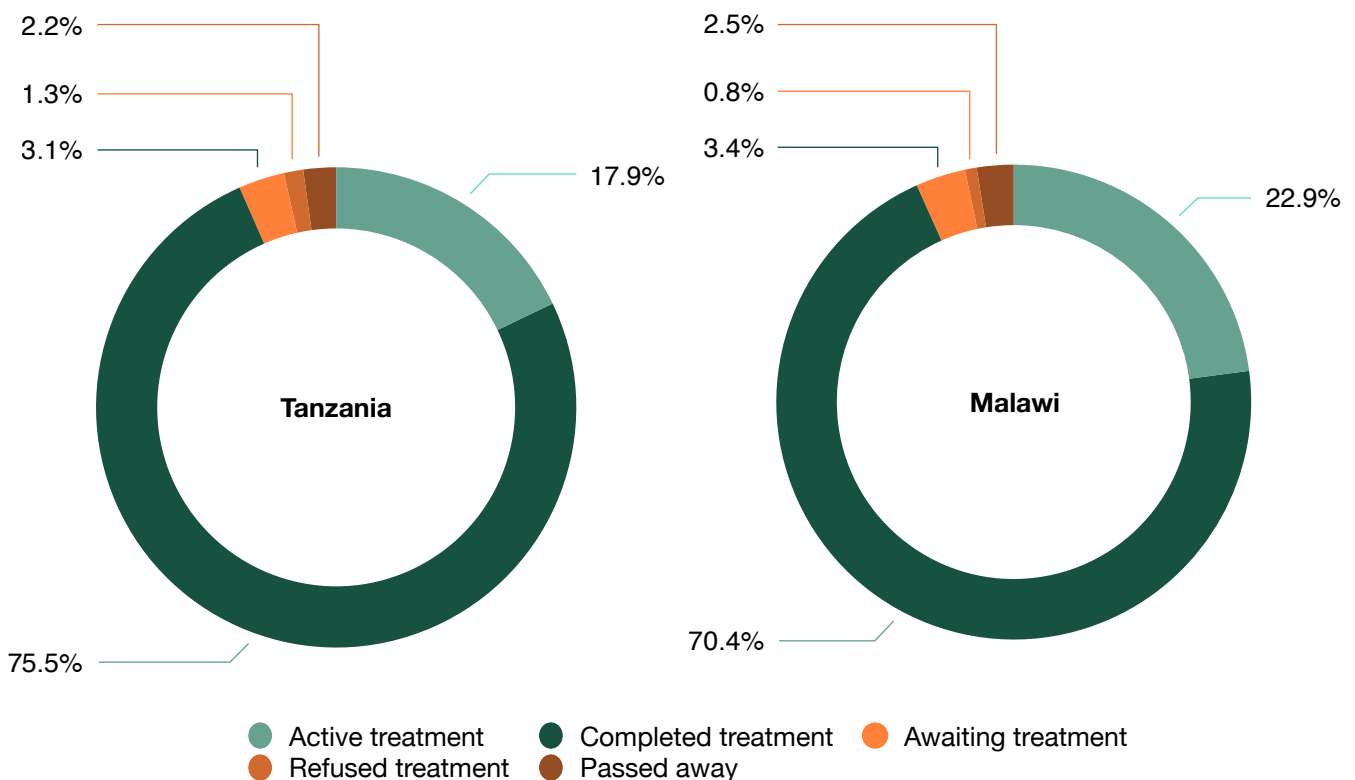
From January to December 2022, 347 patients were referred for further treatment by dermatologists at SCPP clinics. This included 229 patients in Tanzania and 118 patients in Malawi.

Patient Referral Status 2022						
Indicator	Tanzania		Malawi		Total	
<b>Total number of patients referred for surgery</b>	<b>229</b>		<b>118</b>		<b>347</b>	
<b>Completed treatment</b>	173	75.5%	83	70.4%	256	73.8%
<b>Active treatment</b>	41	17.9%	27	22.9%	68	19.6%
<b>Awaiting treatment</b>	7	3.1%	4	3.4%	11	3.2%
<b>Refused treatment</b>	3	1.3%	1	0.8%	4	1.2%
<b>Undergoing palliative care</b>	4	1.7%	9	7.6%	13	3.7%
<b>Passed away</b>	5	2.2%	3	2.5%	8	2.3%

Encouragingly, the majority of referred patients have completed their treatment (75.5% in Tanzania and 70.4% in Malawi). Some patients are still in active treatment<sup>4</sup> (17.9% in Tanzania and 22.9% in Malawi), while 3.1% and 3.4% of patients respectively are awaiting treatment.

A small minority of patients have refused treatment due to a number of factors. Patients sometimes refuse treatment in fear, or because of financial or logistical obstacles involved in leaving their homes, jobs or families and travelling to receive treatment.

**Patient referral status 2022**



<sup>4</sup>Patients undergoing palliative care are not included in the pie chart on page 20, and are instead counted within total patients who are in active treatment.

Referral Results						
Indicator	Tanzania		Malawi		Total	
Patients for whom histology results are available	186		86		272	
Confirmed diagnoses <sup>5</sup>	201		96		297	
SCC	89	44.3%	37	38.5%	126	42.4%
BCC	83	41.3%	43	44.8%	126	42.4%
Other e.g. ulcers, benign lesions, warts, cysts etc.	29	14.4%	16	16.7%	45	15.2%

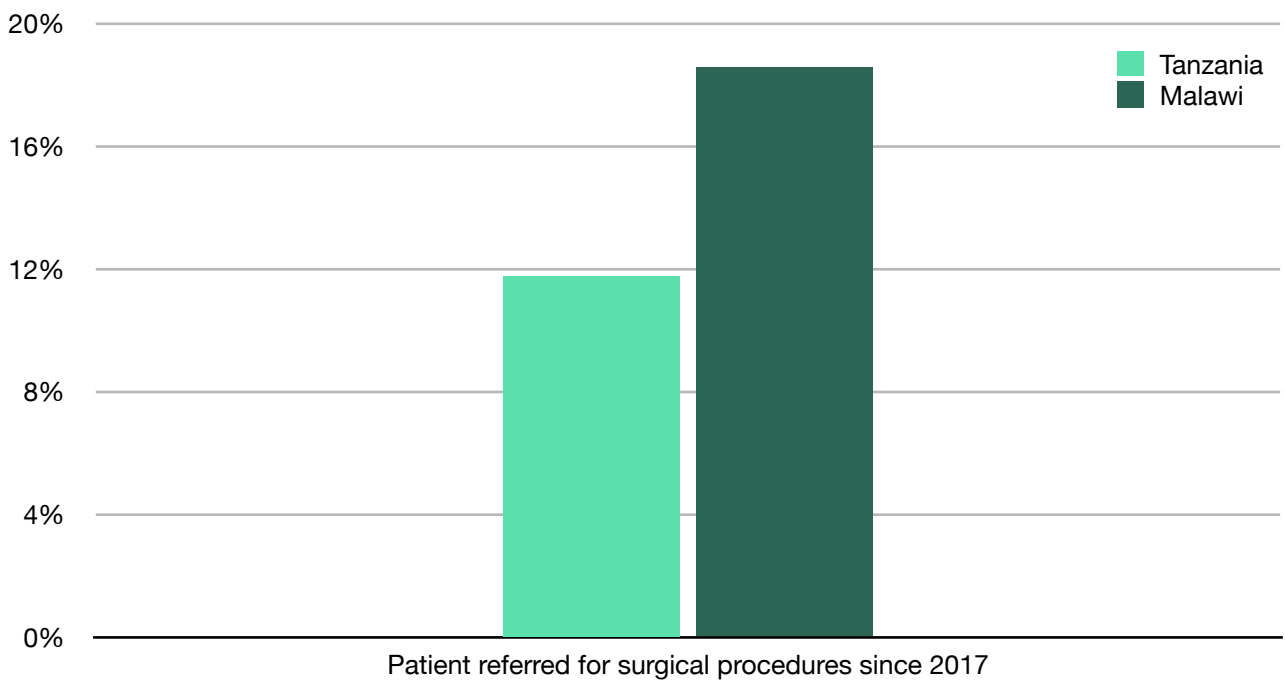
During 2022 we received the histology results of 201 biopsies in Tanzania and 96 biopsies in Malawi. In Tanzania, 44.3% of results were confirmed as SCCs, 41.3% as BCCs, and 14.4% were other conditions, benign or non-cancerous. In Malawi, 38.5% of results were confirmed as SCC, 44.8% as BCC, and 16.7% were other conditions.

In new locations the SCPP continues to see patients with advanced tumours. At the end of 2022 4 patients in Tanzania and 9 patients in Malawi were receiving palliative care support. Sadly 8 patients passed away from skin cancer during the reporting period (5 in Tanzania and 3 in Malawi).

5. Patients often present with multiple lesions and as a result will have multiple biopsies taken. This is why the number of confirmed diagnoses is greater than the number patients with histology results available



## Percentage of all registered patients referred for skin cancer surgery since 2017



11.8% of all registered patients in Tanzania and 18.5% of all registered patients in Malawi have been referred for skin cancer surgery and other treatments since 2017. These are high percentages that demonstrate the scale of the Skin Cancer crises facing people with albinism in Africa, Particular in Malawi where the programme has been operating for a shorter timeframe.



## 4.7 Sun Protection Measures

Indicator	Tanzania		Malawi		Total
	S2 2021	2022	S2 2021	2022	
Number of jars of sunscreen distributed	8,894	14,816	1,722	12,300	37,732
Number of patients receiving sunscreen	3,269	4,651	661	1,521	10,102
Number of sunglasses distributed	0	3,795	15	269	3,254
Number of hats produced locally	4,381	7,458	N/A	N/A	11,839
Number of hats distributed	3,269	7,290	238	1,431	12,236
Number of umbrellas distributed	192	505	0	29	726

During 2022 the SCPP distributed thousands of sun-protective items across Tanzania and Malawi. In Tanzania this included 14,816 pots of sunscreen, 7,290 wide-brimmed hats, 505 umbrellas and 3,795 n. In Malawi this included 12,300 pots of sunscreen, 1,431 wide brimmed hats, 29 umbrellas, and 1,521 UV protective sunglasses.

Since the start of the phase II project in July 2021, a combined total of 65,787 sun protective items have been distributed across Tanzania and Malawi. This includes 11,839 wide brimmed hats which were manufactured locally by tailors with albinism at the Umoja Training Centre in Tanzania, and distributed free through the SCPP. Additionally during 2022 we began exporting and distributing these hats in Malawi for the first time.

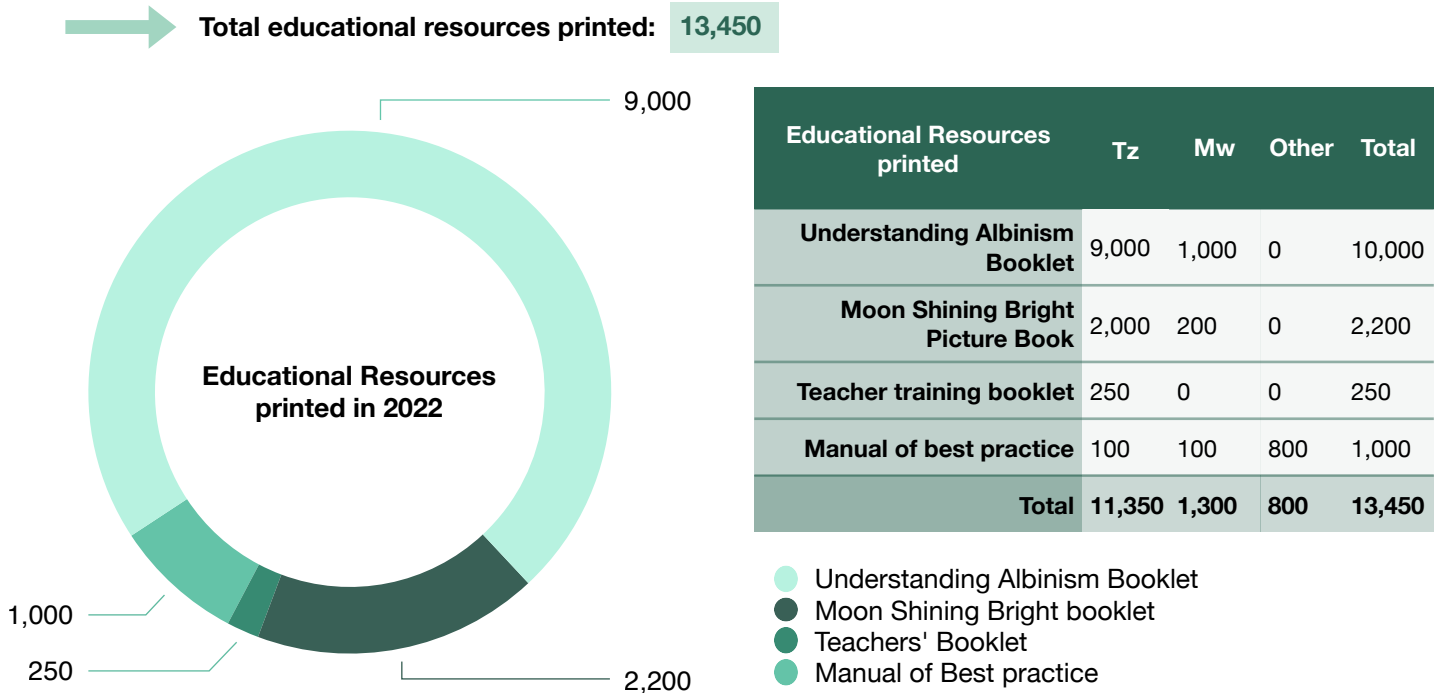


*Children wearing wide brimmed hats manufactured at the Standing Voice Umoja Training Centre on Ukerewe Island, Tanzania. 11,839 locally made hats have been distributed through the SCPP since July 2021*

## 4.8 Educational resources

The SCPP provides an important avenue for the dissemination of specialist educational resources. Standing Voice has developed a wide range of booklets, films, and pop-up theatre performances to train and educate patients, communities and service providers. During 2022 we printed 13,450 education resources in the form of brochures, booklets and manuals which were distributed across all programme areas to people with albinism, their families and service providers. 11,350 of these were for distribution in Tanzania and 1,300 in Malawi. Whilst 800 were for distribution in other African countries.

To support capacity building for health professionals, we continued to distribute and utilise the ‘*manual of best practice in dermatological care for patients with albinism*’ during the delivery of training



Throughout 2022 these resources were disseminated through dermatology and vision clinics, counselling sessions, training events, and directly in schools. They included:

- An information booklet for people with albinism called ‘*Advice and Support for People With Albinism, Families and Caregivers*’ available in Swahili and Chichewa
- A children’s story and picture book (written by Dutch illustration duo Happy Made By) called *Moon, Shining Bright!*, which centres around the life of a fictional young girl with albinism called Moon
- A teacher training booklet called ‘*Albinism: An Information Booklet for Teachers*’ available in three languages
- The Manual of Best Practice for skin cancer management of patients with albinism (Available in French and English).

In 2022 we also introduced screenings of educational films about albinism and human rights in waiting areas at Vision clinics. These films included an animated adaptation of children’s story book *Moon, Shining Bright!* – developed by our partner Inside the Same, which won the 2021 Watoto International Film Festival in Zanzibar – as well as [Jikubali](#), a documentary funded by the Swedish Institute Creative Force and co-produced by Standing Voice, the Tanzania Albinism Society, and Imagine What We Can Do.

By sensitising patients and their duty bearers to understand and address the challenges arising from life with albinism in Tanzania and Malawi, these written and visual resources play a critical role in enabling thousands of people with albinism to take charge of their health and claim their rights.

## 4.9 Community Knowledge

	Indicator	Tanzania	Malawi	Total
	Number of awareness sessions	386	141	527
	Number of patients and their relatives present at awareness sessions	18,047	5,467	23,514
	Number of communication tool(s) used for the general public	4	3	7
	Number of communication tools printed	11,350	1,300	12,650
	Number of communication tool(s) distributed in the form of a brochure	11,168	1,223	12,531
	Number of community advocate training events	4	3	7
	Number of 'community advocates' trained	53	44	97

During the last 12 months the SCPP delivered 527 health awareness sessions across Tanzania and Malawi, to an audience of 23,514 people, including patients, their friends, families, teachers and community representatives. In Tanzania, 386 sessions were delivered to an audience of 18,047 people, with an average of 1.9 awareness sessions per clinic. In Malawi, we delivered 141 sessions to an audience of 5,467 people, with an average of 1.7 sessions per clinic. We also distributed a total of 11,268 and 1,263 education brochures to people with albinism and their families in Tanzania and Malawi respectively.

We delivered Community Advocate Training in 5 new districts in Malawi and 3 regions of Tanzania. These focused on training for Health Surveillance Assistants, Social Welfare Officers and District Committee members of Albinism Associations to protect and advocate for the welfare of people with albinism in between clinic cycles. Across both countries 97 people were trained this year.



## 4.10 Stakeholder Training

As well as providing health education for patients and families, the SCPP promotes systemic change in Tanzania and Malawi by strengthening the ability of health workers to prevent and treat skin cancer in people with albinism.

During 2022 we delivered 10 stakeholders engagement workshops. Each workshop took place prior to launching new SCPP clinical services in new districts of each country. These workshops are designed to introduce the SCPP to relevant stakeholders, map hospitals, health centres and patient populations, so we can identify optimal clinic locations prior to launching the SCPP. The workshops also include sessions on understanding albinism, importance of health education, clinic set-up, data collection and referral management for different stakeholder groups. Across all these events we trained 54 stakeholders in Tanzania and 84 new stakeholders in Malawi. Participants attending ranged from Regional Administrative Secretaries, District Medical Officers, District Social Welfare Officers, Special Education Officers, Medical Officers in-charge, and district and regional representatives of the Tanzania Albinism Association Society (TAS) and Association of Persons with Albinism in Malawi (APAM).

This year we delivered training to 188 health personnel. 75 of these were in Tanzania and 113 in Malawi. Trainees included Dermatology Officers, Clinical Officers, Medical Assistants, nurses and Health surveillance Assistants. Training in both countries consisted of 1 or 2 theoretical classroom-based training days, and an additional 3-5 practical clinic based training days for Dermatology Officers.

In December, as part of our clinical training we delivered a week-long Surgical Camp in Malawi. Training was led by experienced Irish Plastic Surgeon Dr Patricia Eadie and Standing Voice Advisory Board member and GP Dermatologist Dr Mark Wheeler, and was assisted by Dr Esther Mzumara from Kamuzu Central Hospital in Lilongwe. The event trained 15 trainees, which included surgeons and dermatology officers. In addition 21 patients with albinism received skin cancer surgery, and 6 patients were provided with palliative support and counselling. The Surgical Camp was also supported by 13 hospital support staff from Nkhoma Mission Hospital (including nurses, theatre and ward staff), and 6 staff from Standing Voice Malawi.

According to **Patrick Bango** a Dermato-Venereology Officer from Mulanje District:

*"I was privileged to be one those selected to be part of the Nkhoma Surgical Camp. The live video feed was very helpful because it meant the theatre room wasn't congested, and at the same time, clinicians were able to follow each procedure that was happening in the theatre. When we were not operating ourselves, the live video helped us to see how more complex lesions were being excised".*





The table below shows the large number of actors working across the programme. Today there are 1,496 people involved in delivering the SCPP.

By the end of 2027 we aim to have trained and mobilised over 2,500 frontline workers to lead the delivery of this programme.

SCPP stakeholders	Tanzania	Malawi	Total
<b>Dermatologists and Dermatology Officers</b>	29	20	49
<b>Albinism Association leaders</b>	270	121	391
<b>Social Welfare Officers &amp; Health Surveillance Assistants</b>	153	96	249
<b>Other health personnel: Clinicians, Medical Assistants, Nurses, Surgeons, Histopathologists</b>	199	138	337
<b>Regional &amp; District Medical Officers</b>	102	14	116
<b>First responders / counsellors</b>	22	8	30
<b>Optometrists</b>	14	-	14
<b>Special Education Officers (Regional &amp; District)</b>	104	-	104
<b>Teachers</b>	167	-	167
<b>Tailors</b>	17	-	17
<b>Pharmacists</b>	8	14	22
<b>Total</b>	<b>1,085</b>	<b>411</b>	<b>1,496</b>

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## 5. VISION AND EDUCATION PROGRAMME

People with albinism are visually impaired as a result of their melanin deficiency. Untreated, visual impairment can undermine educational outcomes and restrict professional opportunities for people with albinism in Africa, damaging their economic security and forcing many into outdoor labour as subsistence farmers, where the risk of skin cancer is high. In Tanzania and Malawi, limited affordability and availability of specialist optometry services together with systemic discrimination mean most people with albinism do not access the vision care and education they need. Most teachers are also not trained to understand or manage the visual impairment of students with albinism in school.

Since 2014, Standing Voice has been delivering a clinical programme of care, education, and training to improve the vision of people with albinism and strengthen the skills of optometrists and teachers to better cater for their needs. Focusing mainly on students, the programme delivers a network of eye-clinics that provide specialist low vision examinations and assistive devices including monocular telescopes, prescription glasses, Sunglasses, health education and resources.

The Vision Programme is conducted in partnership with the Government of Tanzania and a range of civil society actors. As of Dec 31st 2022, there were 2,903 patients registered in the Vision Programme across 9 regions of Tanzania, while the programme will expand to Malawi for the first time in 2023.



## 5.1 Key Achievements in 2022

### → Total people with albinism supported: 1,851

The Vision Programme delivered five large-scale eye clinics in 2022, serving 1,851 people with albinism. Patients were mobilised from across eight regions in Tanzania including - Mwanza, Arusha, Dar es Salaam, Dodoma, Tabora, Shinyanga, Kilimanjaro and Pwani. All patients received a one-to-one consultation and eye examination from a trained optometrist, education on albinism and visual impairment, and resources and devices to support their management of low vision in daily life.

### → Total assistive vision devices distributed: 7,725

Throughout 2022, we distributed 7,725 assistive devices including 1,235 pairs of prescription glasses, 3,795 pairs of sunglasses, 1,478 monocular telescopes, 1,195 glasses cases and 22 dome magnifiers.

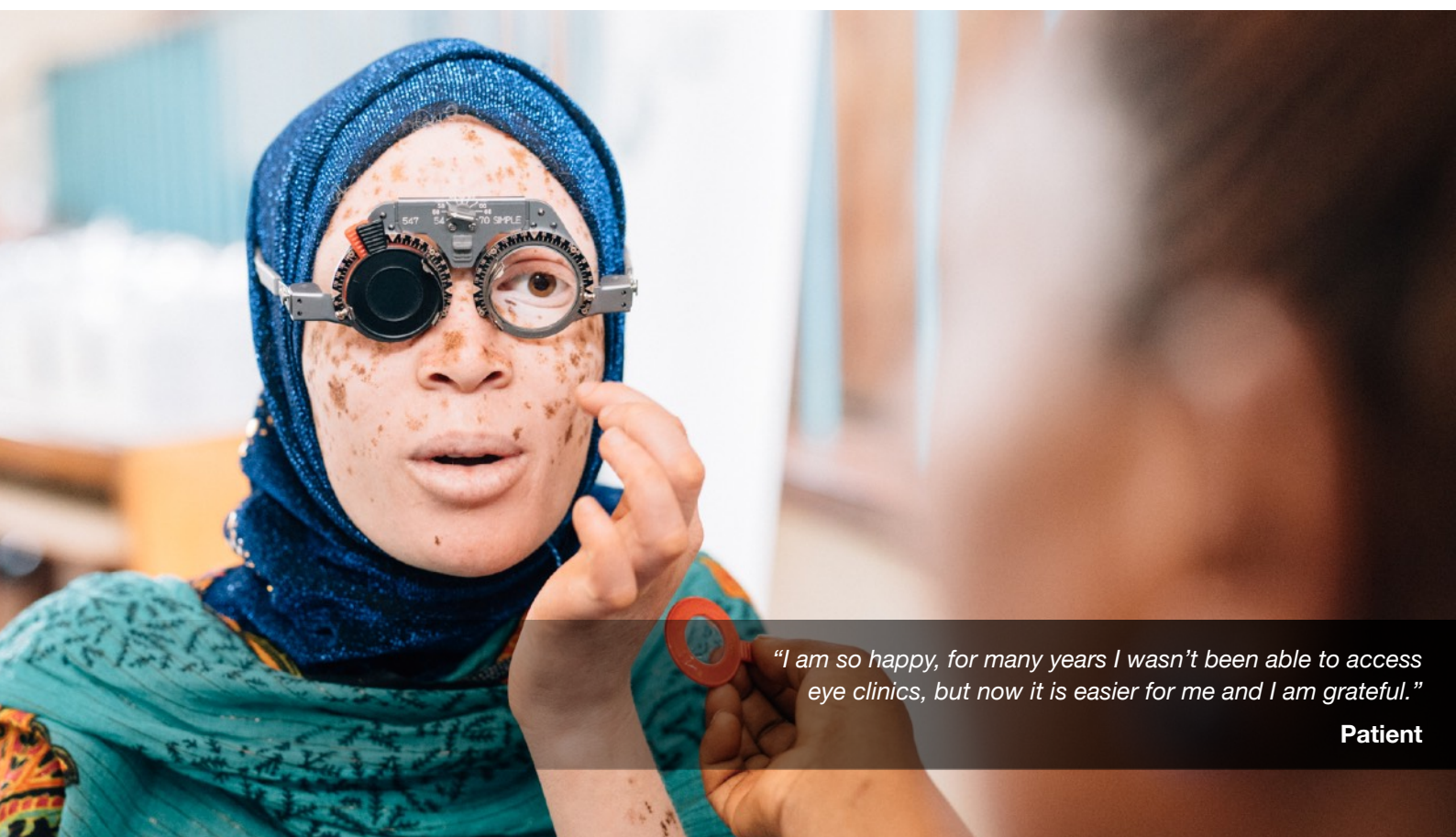
### → Teachers trained: 167

Throughout 2022, the Standing Voice Team delivered specialist training on albinism and inclusive education for 167 teachers across 15 schools in Tanzania. In each of these schools, our staff conducted 'barazas' and parades to build knowledge of albinism across the student body. We estimate that 4,500 pupils and a further 9,000 family and community members of these students were reached across these engagements.

### → Students reached through Hero Visits: 4,500

In addition to eye clinics, we were delighted to introduce a new component of the Vision Programme in 2022. In partnership with 15 schools, we coordinated a series of Albinism Hero Visits whereby inspirational figures with albinism were invited to schools to deliver special talks to engage students and promote positive messages around albinism and personal achievement. Conducted in parallel with our main clinical programme, this series of events delivered one-to-one support for 87 students with albinism while delivering wider sensitisation to 4,500 students across the target schools.

Please see the 2022 Annual Vision Programme Report for a detailed update of the programmes impact this year.



*"I am so happy, for many years I wasn't been able to access eye clinics, but now it is easier for me and I am grateful."*

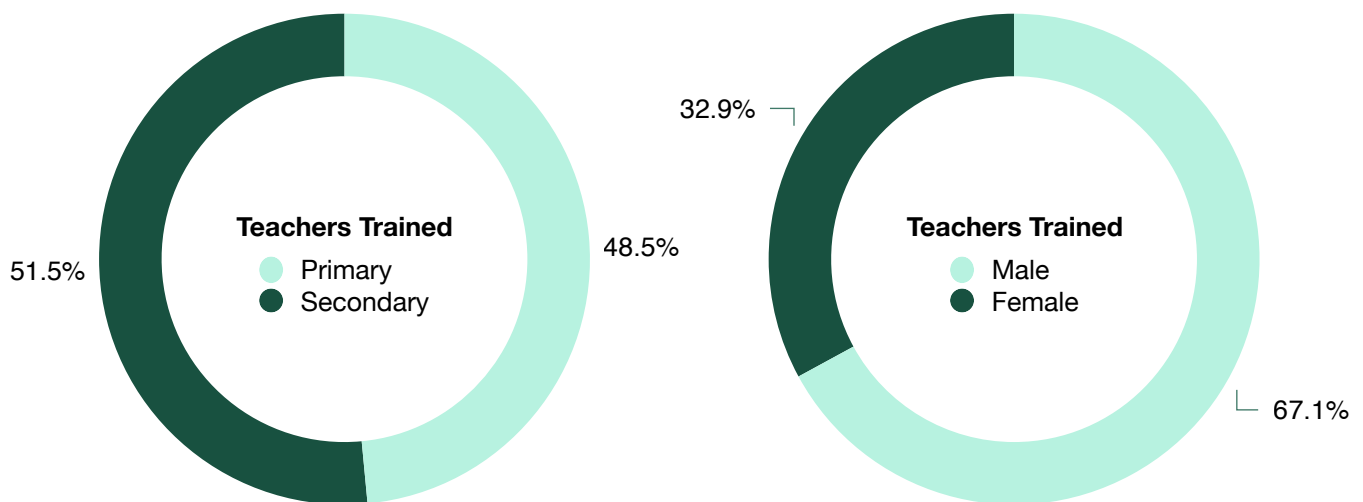
**Patient**

## 5.2 Impact on Education

### 5.2.i TEACHER TRAINING

As well as providing direct clinical care, the Vision Programme aims to achieve systemic change in Tanzania by strengthening the capacity of teachers to understand and mitigate the effects of visual impairment on the education of students with albinism. This is critical for enabling the next generation of people with albinism to reach their educational and professional potential, breaking the long-term cycle of stigma.

	Teachers Trained in 2022		
	Male	Female	Total
Primary	48	33	81
Secondary	64	22	86
Total	112	55	167



Throughout 2022, Standing Voice partnered with 15 schools across four regions of Tanzania to provide specialist training for 167 teachers.<sup>7</sup> Tasked with monitoring and promoting the welfare of students with albinism, these teachers act as Vision Ambassadors who create a culture of respect, solidarity and mutual accountability in safeguarding the rights of these students in their schools; they also function as an important referral link with the main clinical service, reporting to Standing Voice on students' ongoing vision needs and ensuring the correct use and maintenance of prescribed assistive devices. This reciprocity between teacher training and clinical care is strengthened by the increasingly prominent role of optometrists, who travel to schools with the Standing Voice Team to support the delivery of teacher training and provide follow-up care to students in the wake of our main clinical service.

In partnership with Standing Voice, Vision Ambassadors and senior leaders across these 15 schools have developed and implemented tailored action plans to improve the educational participation and welfare of students with albinism. Remedial measures have included:

- the production of large-font examination papers, repainting of blackboards, improvement of classroom lighting systems, and adjustments to classroom seating positions to alleviate barriers to accessibility for students with albinism

7. Despite the roughly equivalent proportions of primary and secondary teachers trained, we acknowledge the unfortunate gender disparity among trainees, the majority of whom were male (particularly in secondary schools). We always endeavour to achieve gender parity in the mobilisation of trainees, and moving forward will look to reach greater numbers of female teachers in these schools where they are available and willing to participate.

- the provision of additional after-class support for students with albinism
- the delivery of awareness-raising assemblies on albinism
- the promotion and monitoring of sun protection measures, including the application of sunscreen and use of sun protective clothing by students with albinism
- the encouragement of students to respect their peers with albinism and support their needs, for example by reading aloud from textbooks or the blackboard

Through the implementation of these measures and promotion of greater understanding of the rights and needs of people with albinism across these 15 schools, we estimate that 4,500 students and an additional 9,000 family members have been sensitised. Focus group discussions have moreover revealed a broad improvement in the self-reported educational welfare and attainment of students with albinism, while Likert-scale surveys have shown growth in teachers' understanding of albinism as well as their confidence in responding to the needs of students with albinism. Key findings have also been disseminated to a range of stakeholders in Tanzania across the health and education sectors, civil society, media and local and national government, establishing a cross-sectoral dialogue around the needs of students with albinism and helping to embed these lessons in contemporary teaching practice.

### Teacher Testimonials

*"Many students are now encouraged to wear long-sleeved clothing, whereas previously most of us teachers were not aware of the risks of UV radiation and the skin cancer situation for these students."*

*"I have shared my knowledge on albinism and low vision with the entire student community. This is an impact from the Standing Voice training program for teachers and I have enjoyed imparting this knowledge."*

*"I have learnt how important it is to listen to students with albinism. We can then understand their needs and find ways of helping them to excel in their academic goals."*



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### 5.2.iii HERO VISITS

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To complement teacher training and expand our engagement with schools, Standing Voice has recently introduced Hero Visits as a new component of the Vision Programme. These celebratory events provide an opportunity for inspirational figures with albinism to visit schools with our team and deliver talks for students with albinism and the wider school community. Alongside these inspirational talks, we run talent competitions with prizes, interactive seminars, book readings, and film screenings.

87 students with albinism enjoyed one-to-one interaction with visiting heroes in 2022, although the wider assemblies are estimated to have reached 4,500 students in total.

#### 2022 Heroes

Judith Mpita, a teacher with albinism and graduate of Education in Special Needs from the University of Dodoma:

*“I was so excited to talk to students about [...] my educational path and life journey. I talked about various academic and social challenges that I went through, and shared the different techniques that I used to overcome those challenges. I believe that the inspiration will be fruitful, because I showed them the ups and downs that they might face on their educational journeys. I did not forget to mention how important it is that they always remain confident (with no fear) when searching for the solutions towards the challenges they face. I strongly believe that students with albinism have a bright future ahead of them and I thank Standing Voice for offering me the opportunity to inspire them.”*

Bryson Yohana Mwayinga, gospel artist with albinism and Season 12 winner of Tanzanian TV talent show Bongo Star Search:

*“In my inspirational talks, I specifically insisted that “disability can happen to anybody at any moment” completely out of the blue. Therefore we should never let our disability affect our passion. I spoke about the hard work that made me become a successful winner of the 2022 National talent show. Without this [hard work] my talent could have gone wasted. I had the passion to explore. I encouraged students to always remain passionate and focused to pursue their professional and personal ambitions, despite the challenges they will face along the way. Many thanks to Standing Voice and I hope we can expand these talks to many other schools to achieve the widest possible impact.”*



*“I feel very proud to be part of a team that is creating such an impact for thousands of people with albinism through this eye care programme. People with albinism greatly appreciate this excellent programme that Standing Voice is delivering across the country.”*

**Standing Voice Staff Member**

*“I’m so proud of the work we are doing at Standing Voice to train more optometrists as experts in low vision management. Together we are bringing transformational eye care to thousands of people with albinism, giving patients the tools and knowledge they need to excel in life.”*

**Dr Abdi Nyembo, Head Programme Optometrist and trainer**



### 5.3 Training of Optometrists

To strengthen access to eye care for people with albinism in Tanzania, Standing Voice partners with the Tanzania Optometric Association, the Kilimanjaro Christian Medical Centre School of Optometry and a network of international experts to train optometrists in the diagnosis and treatment of low vision in this population. There are currently 9 optometrists actively working within the Vision Programme, while 14 in have been trained to date.

As part of this ongoing initiative, we held a dedicated optometry training workshop in Dar es Salaam in October. The first day of training was classroom-based, reviewing core theory on the complex vision needs of people with albinism, including refractive, prescribing and dispensing strategies, and how to deliver specialised vision screening. The days that followed allowed optometrists to practise their newly honed skills in a clinical environment, using our electronic patient management system CommCare and working directly with patients.

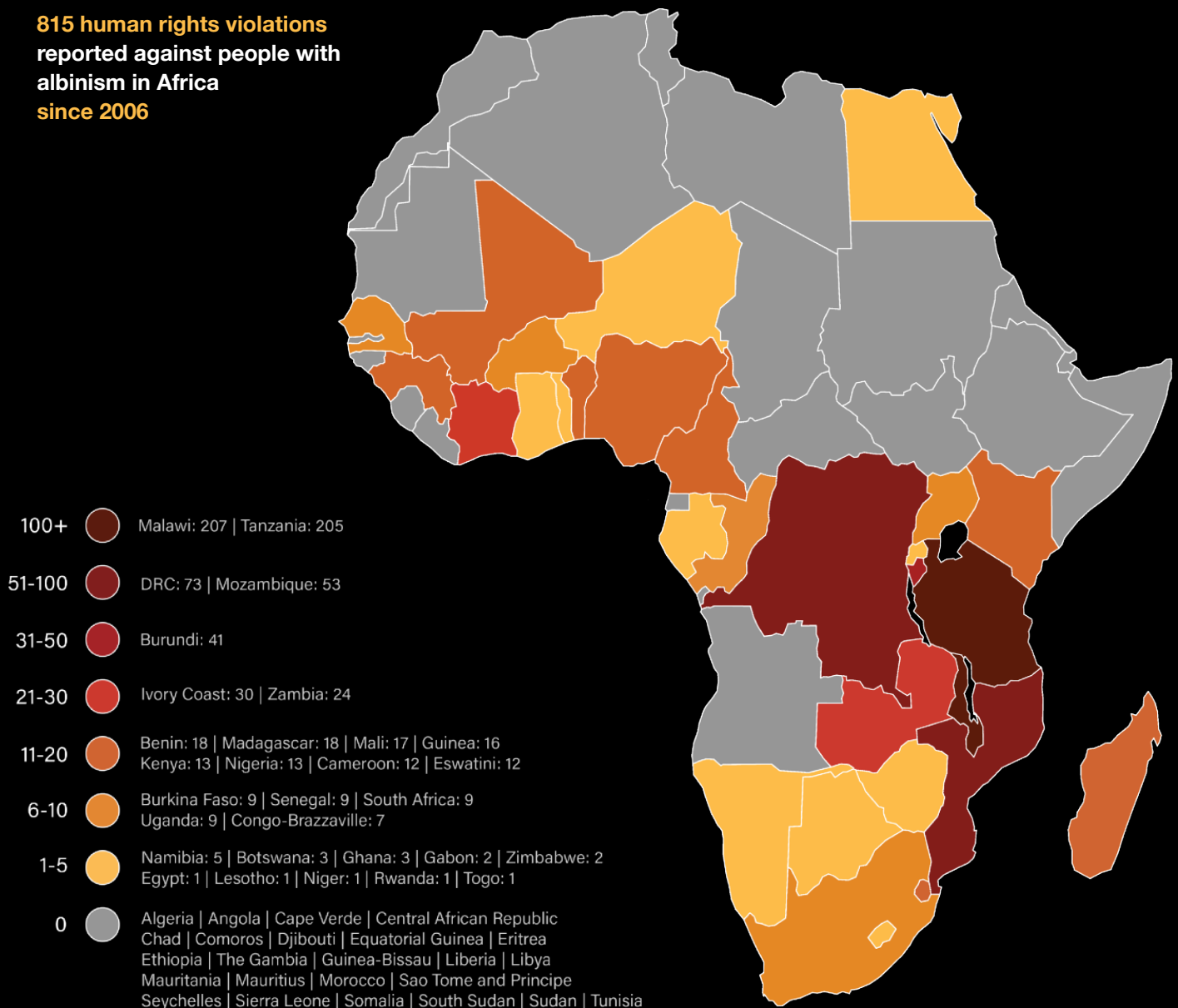
We are grateful for the tenacity and leadership of Dr Abdi Nyembo, an optometrist and tutor at the Kilimanjaro School of Optometry, who oversees the delivery of patient care and optometric training. We express thanks also to Dr Rebecca Kammer, a world-leading expert in the low vision of people with albinism and long-term strategic advisor in the Vision Programme; and to Professor Susan Primo, the Director of Optometry and Vision Rehabilitation Services at the Emory Eye Center and Professor of Ophthalmology at the Emory University School of Medicine, who attended the latest workshop as a visiting specialist and will continue to provide support to clinical development of the Vision Programme moving forward.

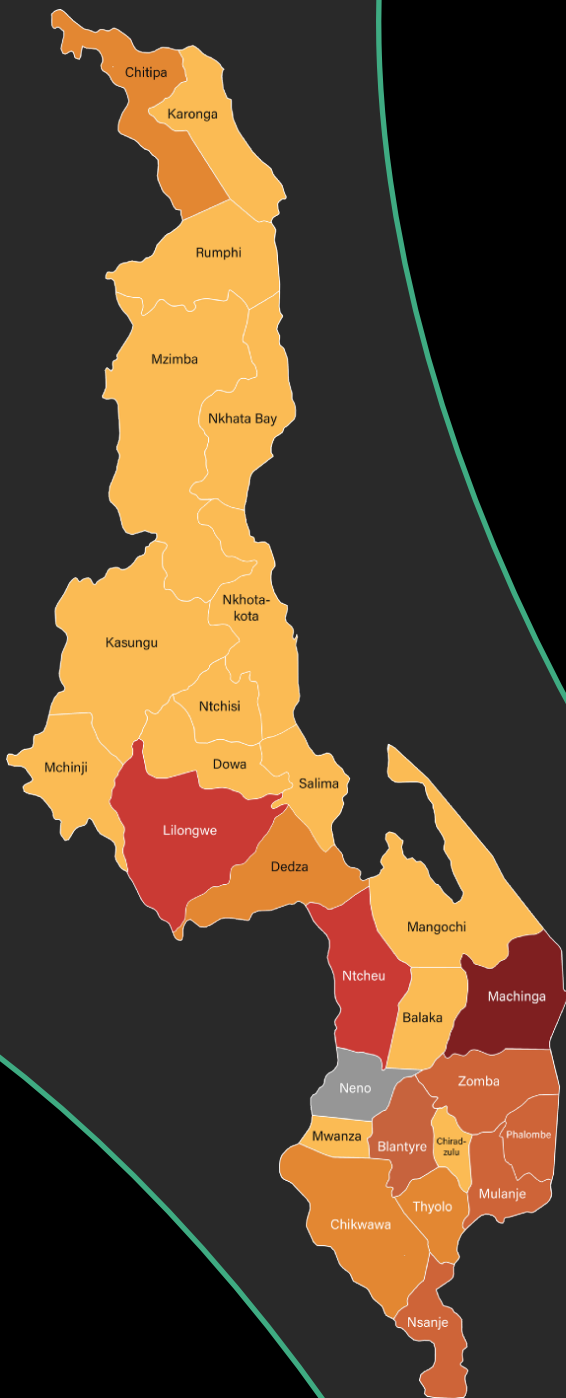
## 6. WELFARE AND SOCIAL PROTECTION PROGRAMME

### 6.1 The Issue

People with albinism are a violently persecuted minority in many African countries. Stigmatised for their unique appearance, many people with albinism are denied opportunities, excluded from services and subjected to damaging myths and misconceptions. In the worst cases, people with albinism are abducted, mutilated, raped and murdered: all because of the colour of their skin. Tanzania and Malawi have been the continental epicentres of these atrocities; together, these two countries account for half of all human rights violations reported against people with albinism across the continent since 2006. The last 6 months of 2022 have seen a tragic resurgence of violence in both countries, with a string of attempted abductions, attacks and killings sending shockwaves through the albinism community. In December 2022, we shared the breaking news of the mutilation and murder of a three-year-old girl with albinism in the Kasungu district of central Malawi, who was asleep in bed with her grandmother when an unidentified assailant broke into the house, stabbing the young girl and amputating her arm.

**815 human rights violations**  
reported against people with  
albinism in Africa  
since 2006





## MALAWI

### 207 human rights violations

reported against people with albinism since 2006

- 30+ ● Machinga: 37
- 16-30 ● Ntcheu: 17 | Lilongwe: 16
- 11-15 ● Zomba: 15 | Mulanje: 13 | Phalombe: 12 | Blantyre: 11 | Nsanje: 11
- 6-10 ● Dedza: 9 | Chitipa: 8 | Thyolo: 8 | Chikwawa: 7
- 1-5 ● Mangochi: 5 | Balaka: 4 | Salima: 4 | Chiradzulu: 3 | Karonga: 3 | Mchinji: 3 | Mwanza: 3 | Ntchisi: 3 | Dowa: 2 | Kasungu: 2 | Mzimba: 2 | Nkhata Bay: 2 | Nkhatakota: 2 | Rumphu: 1
- 0 ● Neno

### Most recent killings:

#### Malawi, 30th November 2022

3-year-old girl with albinism attacked and killed in Kasungu, central Malawi

#### Tanzania, 2nd November 2022

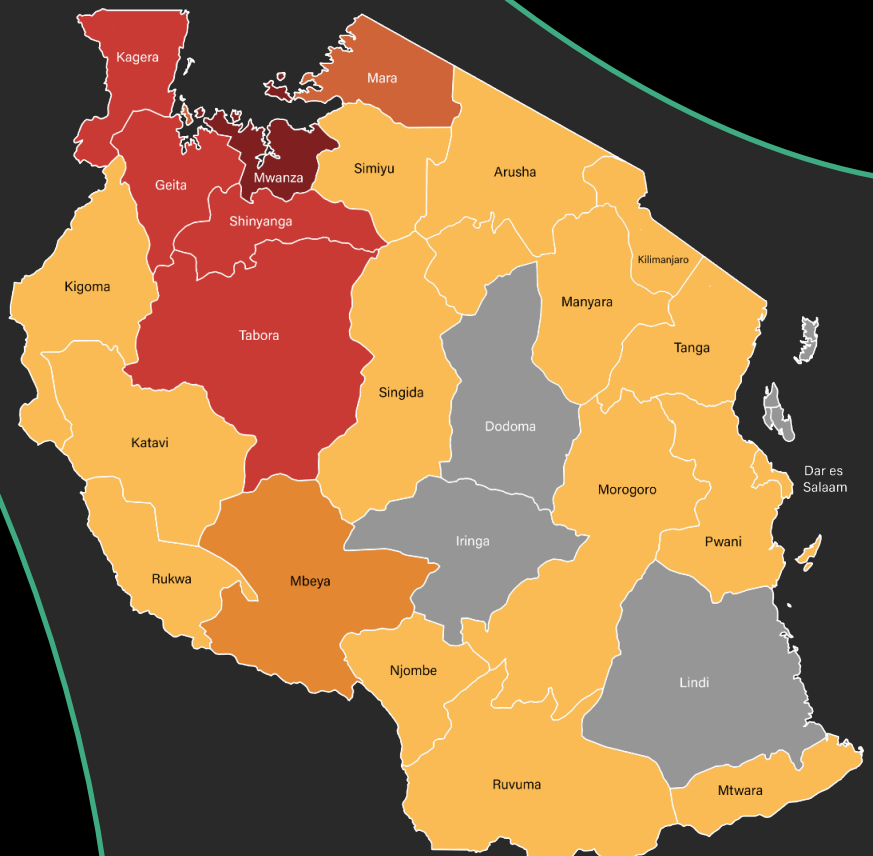
49-year-old man with albinism mutilated and murdered in Mwanza, northern Tanzania

## TANZANIA

### 205 human rights violations

reported against people with albinism since 2006

- 30+ ● Mwanza: 55
- 16-29 ● Kagera: 24 | Geita: 17 | Shinyanga: 17 | Tabora: 16
- 11-15 ● Mara: 14
- 6-10 ● Mbeya: 6
- 1-5 ● Rukwa: 5 | Kigoma: 4 | Morogoro: 4 | Pwani: 4 | Arusha: 3 | Dar es Salaam: 3 | Simiyu: 3 | Tanga: 3 | Njombe: 2 | Katavi: 1 | Kilimanjaro: 1 | Manyara: 1 | Mtwara: 1 | Ruvuma: 1 | Singida: 1 | Songwe: 1
- 0 ● Dodoma | Iringa | Lindi | Zanzibar | Pemba



Alongside the ever-present threat of violent abuse and entrenched discrimination the majority of people with albinism we work with in Tanzania and Malawi face additional challenges to access education, housing, financial security, justice and political representation. Many are survivors of trauma and require specialised support to navigate this range of challenges.

Operating throughout Tanzania and Malawi, the Standing Voice First Response Team works on the front line to identify, intercept and rectify cases of abuse or discrimination against people with albinism and their families. Comprising local Standing Voice staff, social welfare professionals and individuals with first-hand experience of albinism-related stigma, the First Response Team has spent the last three years undergoing a programme of training with Dr Mark Fish, a world-leading expert in trauma recovery and a member of the Standing Voice Advisory Board. The First Response Team is a lifeline for the most vulnerable individuals supported by Standing Voice. Its key pillars of interventions in 2022 included:

### 6.2 Albinism Helpline

Indicator	Tanzania	Malawi
Regions where people with albinism have access to a helpline	17	12
Calls received through helpline	1,575	474
Calls categorised as urgent	N/A	64

In 2022 we continued to develop and operate a dedicated emergency helpline for people with albinism and their families to report incidents of abuse and share any concerns about their health, welfare or security. The team assesses callers’ needs and determines the appropriate course of action, such as over-the-phone advice, referral to an existing Standing Voice programme or to a specialist partner, or alerting of law enforcement in cases where an imminent threat is identified.

Since its establishment in 2021, our helplines have received 1,575 calls in Tanzania and 474 calls in Malawi. The helpline is advertised in all districts and regions where the Skin Cancer Prevention Programme operates. The most common reasons for contacting the helpline are reports of abuse, actual or anticipated threats to security (such as attacks), urgent medical care, emotional support, access to education, food and economic security. In Tanzania, a large proportion of calls relate to the management of skin cancer referrals.



### 6.3 Advocacy and Access to Justice

Protecting people with albinism from discrimination and violence means raising awareness, building understanding, and creating a climate where their rights are recognised and respected at local, national and global levels.

In 2022 Standing Voice worked with communities throughout Tanzania and Malawi to challenge harmful myths and misconceptions about albinism and strengthen security for people with albinism through the delivery of training to society and building of albinism advocate support network to improve social inclusion and reporting of abuses. We engage a broad spectrum of partners to deliver awareness-raising events, including seminars, [assemblies](#), workshops, [parades](#), celebrations, film screenings, [installations](#), [exhibitions](#) and interactive community-based [theatre](#), [comedy](#) and [music](#).

Standing Voice continues to push beyond national boundaries to generate global accountability for the welfare of people with albinism in Africa. Through our special consultative status with the Social and Economic Council of the United Nations, we are an active contributor to advocacy on albinism throughout the UN system: sharing reports of human rights abuses, issuing recommendations based on our data, and collaborating with the mandate of the Independent Expert on Albinism appointed by the United Nations. We have called for greater international action on this issue and elevated the global profile of albinism in Africa through a series of high-profile films, including our founding documentary [In the Shadow of the Sun](#) and the acclaimed BBC production [Born Too White](#).

Standing Voice also works directly with survivors of witchcraft-related atrocity to facilitate access to justice. In June 2022, Executive Director of Standing Voice Malawi, Bonface Massah, spoke live with Al Jazeera following the announcement of life sentences for convicted perpetrators in the 2018 murder of a man with albinism called Macdonald Masambuka: a case in which a Catholic priest, clinician and police officer were convicted for human trafficking and possession of the victim's remains and a former presidential advisor was implicated but never charged. Our team was key in raising awareness to maintain the high public profile of this case and generate sufficient pressure for justice to finally be delivered.



## 6.4 Counselling and Emergency Support

Indicator	Tanzania	Malawi
Regions where people with albinism have access to counselling at clinics	1	3
People with albinism with access to counselling service at clinics	290	285
People counselled through peer-to-peer counselling at clinics	51	23
Number of clinics with Counselling delivered	9	8

During 2022 peer-to-peer counselling was introduced at a number of Dermatology clinics throughout Tanzania and Malawi, providing safe and confidential spaces for patients to speak freely about their needs and concerns, process trauma, build confidence and access referral for specialist services where required. By the end of 2022, counselling was accessible to 290 people with albinism across one region of Tanzania and a further 285 people with albinism across three districts of Malawi. 74 individuals received counselling during this period, across a total of 17 clinics. 80% of all people visiting counselling stations in Tanzania were women, and 40% were mothers.

For the most vulnerable people with albinism – many of whom carry acute psychological trauma and have survived witchcraft-related atrocities – our First Response Team provides a package of emergency support. This can include relocation to safe-housing, home security improvements; livelihood and food security support; urgent medical intervention; psychosocial, dermatological and palliative healthcare; facilitation of trauma recovery or family reconciliation; and direct advocacy interventions in situations of risk, conflict or exclusion.

In Malawi, through a project funded by the United Nations Voluntary Fund for Victims of Torture, Standing Voice is delivering this full package of support measures to 11 people with albinism who have survived attack, and 21 of their family members. In Tanzania, 26 people with albinism are currently accessing ongoing emergency tailored support packages that include counselling, group therapy and security urgent measures.



- **1 in 3 survivors** we support in Malawi is aged 5-10, while **2 in 3** are below the age of 20
- **9 of the 11** highest-risk survivors we support in Malawi are **female**
- Many survivors report that before the SCPP they had no way of **accessing healthcare**

## 6.5 Livelihoods Training and Art Therapy

	Indicator	Tanzania
People with albinism receiving ongoing skills development or income generation support		56
Community members benefitting from the Umoja Training Centre (UTC), e.g. training, water collection, library services, English classes, community events, businesses renting space, etc.		7,585
Number of school children reached by the UTC		29
UTC tailors trained		17
Hats produced by UTC tailors		11,839

In 2014, Standing Voice founded and constructed the Umoja Training Centre (UTC): a facility providing formal training initiatives to promote integration and shared prosperity for people with albinism and their peers and families across Tanzania's Lake Zone. Home to the Ukerewe Albinism Society and a growing number of community groups, the UTC is a hub of business activity, skills development, and therapeutic rehabilitation for survivors of discrimination and violence. The centre provides a second chance for people with albinism who may have missed out on the opportunity of formal education while growing up. With English language classes and the only library on Ukerewe Island, the UTC maintains an extensive programme of school outreach and is an important resource for raising awareness of albinism and strengthening education locally.

In 2022, the UTC continued to support the capacity development of a range of community groups and 56 individual trainees. Disciplines included tailoring, soap-making, batik, photography, radio production, music, and the performing and visual arts. In particular, through the support of the Foundation Pierre Fabre, we have been able to continue to nurture the development of UTC tailors, who to date have manufactured 11,839 wide-brimmed hats for distribution to people with albinism through a network of 150 hospitals and health centres engaged in the Skin Cancer Prevention Programme across Tanzania and Malawi.



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## 6.6 Human Rights Training

A key objective of our welfare work is to strengthen the capacity of key duty bearers to recognise, monitor and protect the human rights of people with albinism in Tanzania and Malawi. Through workshops, seminars and public engagement, we are building a network of albinism ambassadors encompassing a range of stakeholder groups: the family and community members of people with albinism, health and welfare professionals, teachers, local government representatives, members of law enforcement and the judiciary, representatives of government ministries and national human rights institutes, media professionals, religious and traditional leaders and albinism association representatives.

➔ **People with albinism and family members participating in rights-based training: 6,349**

Operating through dermatology clinics, the First Response Team delivers human rights training to thousands of people with albinism and their families and caregivers. The team leads educational seminars and distributes resources to build understanding of albinism and human rights and raise awareness of best practices for protecting and empowering families impacted by albinism.

By the end of 2022, 6,349 people had received this right-based training at clinics in Tanzania. This activity will be formally introduced in Malawi for the first time in 2023.

➔ **Albinism Advocates trained: 8**

In Malawi, we have partnered with the United Nations Voluntary Fund for Victims of Torture to train a network of Albinism Advocates who can monitor and support the most at-risk people with albinism at the community level. These advocates include albinism society leaders, Health Surveillance Assistants and Social Welfare Officers, many of whom are already engaged in the SCPP and play a critical role in the mobilisation and retention of patients.

By the end of 2022, eight Albinism Advocates had been trained in group therapy and active listening in Malawi, participating in a series of workshops led by international trauma recovery expert Dr Mark Fish and Dr Rim Ismail. This training has equipped these individuals to provide ongoing psychosocial support to people with albinism, tracking any developments in their wider needs and communicating these to the First Response Team.



## 6.7 Women's Albinism Action Group

Women with albinism and mothers of children with albinism face intersectional discrimination and are often uniquely vulnerable to poverty and violence. In Tanzania and Malawi, the myth that intercourse with a woman with albinism can cure infertility and AIDS places this population at disproportionate risk of sexual violence and contraction of HIV. Mothers of babies with albinism are often blamed when a baby with albinism is born, abandoned by their husbands and families and left with sole responsibility for the health, education and physical and economic security of their child. The abandonment of many mothers by their partners also restricts the ability of these women to participate in income-generating activities, further jeopardising the health and security of both mother and child.

Established in 2015 with the support of Standing Voice, the Women's Albinism Action Group (WAAG) is now a registered community-based organisation run by and for mothers impacted by albinism based at the Umoja Training Centre in Tanzania. The group began as an informal collective, meeting to share their experiences and reflect on their challenges as women with albinism or mothers of children with albinism. Over time, bonds of trust and solidarity were strengthened and the group now meets regularly to provide peer support and conduct community advocacy. The group works with Standing Voice and the Tanzania Albinism Society to identify and counsel any new mothers of babies with albinism, travelling to communities where stigma is rife to raise awareness of albinism and advocate for the safety and inclusion of all families impacted by the condition.

By the end of 2022, 18 members of the Ukerewe Women's Albinism Action Group had received specialist training on albinism and peer support. In turn, these women have delivered 5 training seminars on albinism for key welfare professionals, undertaken 15 additional engagements at schools and health centres, and delivered a programme of 38 community outreach events to sensitise a wider audience of 8,355 people in total. WAAG members have also provided training on albinism and sun protection techniques for 84 mothers impacted by albinism on Ukerewe Island. In addition to the main Standing Voice helpline, the WAAG also operates its own dedicated helpline and has supported 469 callers to date.



- **Established at the UTC** as a safety and support mechanism for women impacted by albinism
- A **2-year partnership with the Sir Halley Stewart Trust** enabled Standing Voice to strengthen the capacity of the WAAG through a series of trainings and outreach activities
- The WAAG registered as a **community-based organisation in 2021**
- Today, the WAAG provides **peer counselling** and **helpline support** for women and mothers impacted by albinism; delivers **albinism training for welfare professionals**; and conducts **community outreach** to build public awareness of the rights and needs of people with albinism

## 7. SPECIAL EVENTS

In 2022 we have been very active in advocating for the rights and needs of people with albinism, both at local and international levels.

In June to mark International Albinism Awareness Day we held special events across Tanzania, Malawi and the UK. We also teamed up with the United Nations to host a special screening of BBC documentary *In the Shadow of the Sun*. The film was accompanied by a Q&A with Standing Voice UK Executive Director Harry Freeland, SV Malawi Executive Director Bonface Massah and United Nations Independent Expert on the Enjoyment of Persons with Albinism Muluka Miti-Drummond.

Throughout 2022 Standing Voice was invited to present on its work during a number of international conferences and symposiums. This included a series of presentations in October at the 3rd African Dermatology Conference in Abidjan, Côte d'Ivoire, hosted by the Foundation Pierre Fabre; and November during the International Scientific Conference on Albinism (ISCA) hosted by the Global Albinism Alliance.

We also held press events and celebrations marking Skin Cancer Awareness Month and World Sight Day. We were visited by representatives from the President's Office TAMISEMI, the Prime Minister's Office, the National Eye Coordinator and other Ministry of Health representatives, Regional and District Education Officers, and national and regional leaders of the Tanzania Albinism Society and Association of Persons with Albinism in Malawi. Our special guests received tours of our services and gave special addresses at key landmarks throughout the year. These events were documented on radio and TV stations across Tanzania and Malawi airing on MBC, TBC, AZAM and Star TV among others.



## 8. DATA MANAGEMENT

In 2022 we conducted several activities to further develop data collection tools and strengthen the roll out of our custom built electronic data capture system across both countries. During the reporting period the system was active in all SCPP clinic locations across Tanzania and Malawi.

At the start of the year we built and piloted new data collection tools to support the Vision Programme. During its development we worked with Low Vision experts on albinism, members of the Standing Voice Advisory Board and Optometrists in Tanzania to gather as much expert input as possible. We first conducted a pilot, and delivered training to Optometrists before launching the new tools at a large-scale eye clinic held in Mwanza in May 2022. We purchased 17 new tablets to support expansion during 2022.

Feedback from Optometrists, staff and patients has been extremely positive. All reported that registration and eye examinations were more efficient, reducing waiting times and increasing the number of patients who can be seen during a clinic day. By the end of 2022, the system was operational across all Vision clinic locations in Tanzania.

In both countries, we continued delivering training to health professionals in the use of our data capture system. These health workers included Dermatologists, Dermato-Venereology Officers, Clinical Officers, Medical assistants, Optometrists and staff. Today, there are 115 personnel actively using the system in the field.

	No. of people trained
<b>Tanzania</b>	41
<b>Malawi</b>	74
<b>Total</b>	<b>115</b>



## 9. FUNDING MATTERS

### GRANT-MAKING POLICY

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The charity's policy is to make grants to collaborating organisations who are in need of funds to deliver a service in partnership with Standing Voice. On occasion the trustees may decide to give a grant to a beneficiary organisation that is not working in partnership with Standing Voice, but is working towards a shared objective of the charity.

In line with our current activities the organisation or service funded must promote the wellbeing and social inclusion of people with albinism in Africa through advancing health, education, welfare or community-based projects and services.

All grants are awarded on the condition of robust accounting and financial reporting standards; strength of internal policies and procedures (including safeguarding, finance and procurement policies); past records of grant management and successful implementation; and compliance with all relevant regulations and international standards as defined by Standing Voice in its grant contracts.

### FUNDRAISING ACTIVITIES IN THE UK

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Standing Voice applies for grants from trust funds, grant-giving foundations and institutions, and corporate donors. Standing Voice also raises funds donated by individuals reached through direct approaches and by holding planned fundraising events and campaigns.

The charity's principal sources of funding during the year have consisted of grant funders and a group of committed philanthropists donating to specific projects.

Throughout 2022 we were proud to be funded by many innovative Foundations and Trust funds including the Pierre Fabre Foundation, the Wellcome Trust, the International Foundation for Dermatology (IFD), the International League of Dermatological Societies (ILDS), the United Nations Voluntary Fund for Victims of Torture (UNVFVT), Essilor Vision for Life, the Sir Halley Stewart Trust, the British and Foreign School Society (BFSS), the John Armitage Charitable Trust, Inside the Same, Mite, Wings of Support, Free A Girl, the Friends of Malawi Association, Esther Ireland, the Evan Cornish Foundation, the Souter Charitable Trust, and many others including those who wish to remain anonymous.

The trustees extend their sincere gratitude to all individuals and grant-givers who have donated to the organisation this year to ensure we continue our vital work.

### FINANCIAL PERFORMANCE

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Income during the period 1st January 2022 to 31st December 2022 amounted to £911,951 (January 2021-December 2021: £446,643). Voluntary income was £911,875 (2021: £446,615). Of the total income, £822,199 (2021: £418,022) was restricted and £89,752 (2021: £28,593) was unrestricted. The restricted income consists of donated funds from grant funders and individuals. £318,389 (2021: £252,853) of restricted funding was carried forward. Unrestricted income was mainly from individual donations.

Expenditure amounted to £777,946 (2021: £563,174) of which £715,371 (2021: £484,988) was project expenditure, £56,600 (2021: £72,847) was fundraising expenditure and £5,975 (2021: £5,339) was governance costs. Of the total expenditure, £706,978 (2021: £512,279) was restricted expenditure and £70,968 (2021: £50,895) was unrestricted expenditure.

Standing Voice exercises a policy of setting aside funds to cover 6 months of administration overheads as reserves, to cover core costs in the event of the organisation encountering a period of reduced income. At

the end of the financial year ending 31st December 2022 the charity carried forward a balance of £437,470 (2021: £303,465), of which £167,439 was available for overheads. The organisation also awaited funding responses from major grant funders. The trustees deemed reserve funds held to be sufficient, keeping in consideration the overheads budget allocations in restricted funds held, and the status of committed funding from new and existing donors due for disbursement in 2023 amounting to over £900,000.

## EXPENDITURE SUPPORTING KEY OBJECTIVES

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Standing Voice has been able to increase expenditure towards its life saving programmes in 2022 to £715,371. This has been vital at a time when our clients' needs are under severe pressure due to worsening global economic conditions, increasing risk of climate change-related disasters, and the sustained threat of attack against people with albinism. This increase in project expenditure (a £230,833 increase on 2021) has been carefully planned and deemed viable based on securing multi-year funding partnerships in 2022. Expenditure on our projects promoting the wellbeing and social inclusion of people with albinism is consistent with Standing Voice's objectives as defined in its governing constitution.

People with albinism in Tanzania and Malawi continue to benefit from capacity development; improved dermatological and ophthalmological health services; innovative trauma recovery interventions; increased access to education; and positive advances in local and international awareness on albinism resulting from Standing Voice's project activity. Additionally, through training and coordination of health, social care and education service providers in 2022 we are proud to be building a sustained, locally driven response to this issue in both countries.

The charity's projects this year have grown substantially both in terms of geographical reach, and depth of the interventions we are delivering across both countries of operation. Whilst growing the footprint of its work Standing Voice is progressively interlinking services, to ensure individual projects act as gateways for other essential services. Scaling up geographical reach, alongside investing in a holistic approach to our work has led Standing Voice to achieve its objective of combating human rights abuses against people with albinism by advancing integration in society in 2022.



## 10. GOVERNANCE AND RISK

### FUTURE PLANS OF THE CHARITY

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In 2023, we will continue to expand the geographical reach of our Skin Cancer Prevention Programme in both Tanzania and Malawi. We will further accelerate our training of community leaders, teachers, health professionals, civil society groups, people with albinism and their families. Our work to empower and build the capacity of people with albinism will develop through increasing our clients' access to information on their own health and welfare, and providing opportunities for them to communicate their perspectives to key stakeholders who have influence on the outcomes of their wellbeing.

Through our partnership with the Pierre Fabre Foundation we will continue adapting our dermatology programme to allow for the phasing in of other complimentary services at clinics, specifically psychosocial support and counselling. In Malawi the inclusion of these other forms of support will be co-funded by the United Nations Voluntary Fund for Victims of Torture and the European Commission. By the end of 2023, counselling available at Dermatology clinics will be accessible to people with albinism and their families across multiple regions and districts in Tanzania and Malawi.

At the end of 2022 we secured funding from new partners including the European Commission. Specifically in 2023 this new EU partnership will enable us to scale up the dermatology, security and psychosocial support we offer people with albinism living with extreme risks to their welfare. We are excited to be working alongside our partners Beyond Suncare and Youth Net and Counselling (YONECO) through this new project.

During 2023 the expansion of our work in Tanzania and Malawi, will be combined with our sustained efforts to continue catalysing action from national governments. We will achieve this through our advocacy work within and beyond these countries of operation, and by through our position as Chair of the National Action Plan (NAP) on Albinism in Tanzania, and as a member of the NAP task force in Malawi.

### RISK

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The primary risk to the charity (and by association its clients) is insufficient staff capacity to meet the growing needs of our target group. As our services increase in scope and depth we are continually evidencing the complexity of people with albinism's life challenges and threats to their welfare. Meeting these challenges demands scaled up investment of resources to ensure we are able to sustain a high calibre and growing team.

We manage this risk through maintaining a varied portfolio of benefactor relationships, and through regular submission of new grant applications, and scrutiny of our expenditure pipeline. This allows us to plan for recruitment well in advance of new appointments, to ensure our team's development is delivered in line with funding commitments and strategy.

Additionally, Standing Voice consistently manages the risk of maladministration at the point of implementation through routine monitoring of our in-country teams in Tanzania and Malawi and deployment of robust control policies. Scheduled finance and activity reports are scrutinised upon submission, as a prerequisite for further fund disbursement by Standing Voice UK. Executive Management also monitors the flow of funds from the UK to our country offices through a two-step forex approval system, which ensures that any transfer between the UK and Malawi or Tanzania is reviewed and approved by two predetermined forex administrators at Standing Voice UK. Additionally, our UK trustees and management regularly visit Standing Voice local offices, partners and project sites to maintain visibility of all aspects of local operation, including potential risks that require new mitigation strategies.

## RESPONSIBILITIES OF THE BOARD OF TRUSTEES

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The Trustees are responsible for managing the affairs of the CIO and may for that purpose exercise all the powers of the CIO.

It is the duty of each charity trustee:

1. to exercise his or her powers and to perform his or her functions in his or her capacity as a trustee of the CIO in the way he or she decides in good faith would be most likely to further the purposes of the CIO; and
2. to exercise, in the performance of those functions, such care and skill as is reasonable in the circumstances having regard in particular to:
  1. any special knowledge or experience that he or she has or holds himself or herself out as having; and,
  2. if he or she acts as a charity trustee of the CIO in the course of a business or profession, to any special knowledge or experience that it is reasonable to expect of a person acting in the course of that kind of business or profession.

The Board of Trustees are responsible for complying with the requirements of the Charities Act 2011 with regard to the keeping of accounting records, to the preparation and scrutiny of statements of account, and to the preparation of annual reports and returns for submission to the Charity Commission.

## PUBLIC BENEFIT

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In accordance with section 17 of the Charities Act 2011 the Trustees confirm that they have had regard to the Charity Commission's guidance in relation to public benefit. The Trustees have referred to the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning the charity's future activities. In particular, the Trustees have considered how planned activities contribute to the aims and objectives they have set.

## TRUSTEES' DECLARATION

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There is no relevant information of which the charity independent examiner is unaware. Each Trustee has taken all the necessary steps that he/she ought to have taken as a Trustee in order to inform themselves of all relevant information, and to establish that the charity's independent examiner is aware of that information.

Approved by the Board of Trustees and signed on its behalf by:



**Sabine Zetteler**

Chair of the Board of Trustees

28/01/2023

## 11. ACCOUNTS

### 11.1 Independent Examiner's Report to the Trustees of Standing Voice

I report on the accounts of the charitable company for the year to 31 December 2022 which are set out on the following pages.

#### Respective responsibilities of trustees and examiner

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 114(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a member of the Institute of Financial Accountants.

Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

examine the accounts under section 145 of the 2011 Act;  
follow the procedure laid down in the General Directions given by the Charities Commission  
under section 145 (5)(b) of the 2011 Act; and  
state whether particular matters have come to my attention.

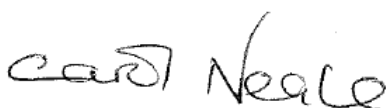
#### Basis of independent examiner's report

My examination was carried out in accordance with the general directions given by the Charities Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a

#### Independent examiner's statement

In connection with my examination, no matter has come to my attention;

- 1) which gives me reasonable cause to believe that in any material respect the requirements:
  - to keep accounting records in accordance with the section 386 of the Companies Act 2016; and
  - to prepare accounts which accord with the accounting records comply with the accounting requirements of section 396 of the Companies Act 2016 and with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities (revised 2015) have not been met; or
- 2) to which, in my opinion, attention should be drawn to enable a proper understanding of the accounts to be reached.



**Carol Neale AFA MIPA**  
GS Verde Accountants  
Maple House  
Cleeve  
Bristol  
BS49 4FS

## 11.2 Statement of Financial Activities (SoFA)

Statement of Financial Activities (Incorporating an Income and Expenditure Account) for the period ended 31 December 2022:

	Notes	Unrestricted funds (£)	Restricted income funds (£)	Total 2022 (£)	Total 2021 (£)
<b>Income and endowments from:</b>					
Donations and legacies		89,676	822,199	911,875	446,615
Other trading activities		-	-	-	-
Income from investments		76	-	76	28
Income from charitable activities		-	-	-	-
Other income		-	-	-	-
<b>Total income and endowments</b>	<b>2</b>	<b>89,752</b>	<b>822,199</b>	<b>911,951</b>	<b>446,643</b>
<b>Expenditure on:</b>					
Raising funds		4,765	51,835	56,600	72,847
Charitable activities		60,228	655,143	715,371	484,988
Other expenditure		5,975	-	5,975	5,339
<b>Total expenditure</b>	<b>3</b>	<b>70,968</b>	<b>706,978</b>	<b>777,946</b>	<b>563,174</b>
<b>Net income/(expenditure) and net movement in funds for the year</b>		<b>18,784</b>	<b>115,221</b>	<b>134,005</b>	<b>-116,531</b>
<b>Net income/(expenditure) before other recognised gains/(losses)</b>		<b>18,784</b>	<b>115,221</b>	<b>134,005</b>	<b>-116,531</b>
<b>Other recognised gains/(losses)</b>					
Gains and losses on revaluation of fixed assets for charity's own use		-	-	-	-
Gains and losses on investment assets		-	-	-	-
<b>Net income/(expenditure) and movement in funds for the year</b>		<b>18,784</b>	<b>115,221</b>	<b>134,005</b>	<b>-116,531</b>
<b>Total funds brought forward</b>		<b>41,574</b>	<b>261,891</b>	<b>303,465</b>	<b>419,996</b>
<b>Total funds carried forward</b>		<b>60,358</b>	<b>377,112</b>	<b>437,470</b>	<b>303,465</b>

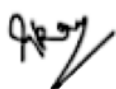
The Statement of Financial Activities includes all gains and losses recognised in the year. All the activities derive from continuing operations during the above periods.

## 11.3 BALANCE SHEET

Balance Sheet as at 31 December 2022

	Notes	Unrestricted funds (£)	Restricted income funds (£)	December 2022 (£)	December 2021 (£)
<b>Fixed assets</b>					
Tangible investments	4	-	7,932	7,932	10,854
Intangible investments					
<b>Total fixed assets</b>		<b>-</b>	<b>7,932</b>	<b>7,932</b>	<b>10,854</b>
<b>Current assets</b>					
Debtors and prepayments	5	21,151	79,323	100,474	60,971
Cash at bank and in hand		48,020	318,389	366,409	261,891
<b>Total current assets</b>		<b>69,941</b>	<b>397,712</b>	<b>466,883</b>	<b>322,862</b>
<b>Liabilities</b>					
Creditors: amounts falling due within one year	6	(8,813)	(28,532)	(37,345)	(30,251)
<b>Net current assets/(liabilities)</b>		<b>60,358</b>	<b>369,180</b>	<b>429,538</b>	<b>292,611</b>
<b>Total assets less current liabilities</b>		<b>60,358</b>	<b>377,112</b>	<b>437,470</b>	<b>303,465</b>
Creditors: amounts falling due after one year		-	-	-	-
Provisions for liabilities and charges		-	-	-	-
<b>Net assets</b>		<b>60,358</b>	<b>377,112</b>	<b>437,470</b>	<b>303,465</b>
<b>Funds of the charity</b>					
Unrestricted funds		60,358	-	60,358	41,574
Restricted income funds	7	-	377,112	377,112	261,891
Endowment funds		-	-	-	-
<b>Total funds</b>		<b>60,358</b>	<b>377,112</b>	<b>437,470</b>	<b>303,465</b>

The financial statements were approved and authorised for issue by the Trustees on 28/01/2023 and signed on their behalf by:



**Gurmeet Kaur**

Treasurer of the Board of Trustee

## 11.4 BASIS OF PREPARATION

Basis of preparation and accounting policies for year ended 31 December 2022

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) – Charities SORP (FRS 102) and the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

### 1. ACCOUNTING POLICIES

*This list of accounting policies has been applied by the charity.*

#### Incoming Resources

<b>Recognition of incoming resources</b>	These are included in the Statement of Financial Activities (SoFA) when: <ul style="list-style-type: none"> <li>- the charity becomes entitled to the resources;</li> <li>- the trustees are virtually certain they will receive the resources; and</li> <li>- the monetary value can be measured with sufficient reliability</li> </ul>
<b>Incoming resources with related expenditure</b>	Where incoming resources have related expenditure (as with fundraising or contract income) the incoming resources and related expenditure are reported gross in the SoFA.
<b>Grants and donations</b>	Grants and donations are only included in the SoFA when the charity has unconditional entitlement to the resources.
<b>Tax reclaims on donations and gifts</b>	Incoming resources from tax reclaims are included in the SoFA at the same time as the gift to which they relate.
<b>Contractual income and performance-related grants</b>	This is only included in the SoFA once the related goods or services have been delivered.
<b>Gifts in kind</b>	Gifts in kind are accounted for at a reasonable estimate of their value to the charity or the amount actually realised. Gifts in kind for sale or distribution are included in the accounts as gifts only when sold or distributed by the charity. Gifts in kind for use by the charity are included in the SoFA as incoming resources when receivable.
<b>Donated services and facilities</b>	These are only included in incoming resources (with an equivalent amount in resources expended) where the benefit to the charity is reasonably quantifiable, measurable and material. The value placed on these resources is the estimated value to the charity of the service or facility received.
<b>Volunteer help</b>	The value of any voluntary help received is not included in the accounts but is described in the trustees' annual report.
<b>Investment income</b>	This is included in the accounts when receivable.
<b>Investment gains and losses</b>	This includes any gain or loss on the sale of investments and any gain or loss resulting from revaluing investments to market value at the end of the year.

## Expenditure and Liabilities

<b>Liability recognition</b>	Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to pay out resources.
<b>Governance costs</b>	Include costs of the preparation and examination of statutory accounts, the costs of trustee meetings and cost of any legal advice to trustees on governance or constitutional matters.
<b>Grants with performance conditions</b>	Where the charity gives a grant with conditions for its payment being a specific level of service or output to be provided, such grants are only recognised in the SoFA once the recipient of the grant has provided the specified service or output.
<b>Grants payable without performance conditions</b>	These are only recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the charity.
<b>Support Costs</b>	Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, e.g. allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

## Assets

<b>Tangible fixed assets for use by charity</b>	These are capitalised if they can be used for more than one year, and cost at least £500. They are valued at cost or a reasonable value on receipt.
<b>Investments</b>	Investments quoted on a recognised stock exchange are valued at market value at the year-end. Other investment assets are included at trustees' best estimate of market value.
<b>Stocks and work in progress</b>	These are valued at the lower of cost or market value.

## 2. ANALYSIS OF INCOME AND ENDOWMENTS

Analysis		2022 (£)	2021 (£)
<b>Donations and Legacies</b>	Restricted income	822,199	418,022
	Unrestricted income	89,676	28,593
		<b>911,875</b>	<b>446,615</b>
<b>Other trading activities</b>		-	-
<b>Income from investments</b>	Bank interest	76	28
<b>Other income</b>		-	-
<b>Total income and endowments</b>		<b>911,951</b>	<b>446,643</b>

### 3. ANALYSIS OF RESOURCES EXPENDED

Analysis		2022 (£)	2021 (£)
<b>Costs of generating voluntary income</b>	Staff costs	44,057	54,109
	Support costs	12,543	18,738
		<b>56,600</b>	<b>72,847</b>
<b>Charitable activities</b>	Staff costs	102,800	126,254
	Support costs	29,266	43,721
	Direct project costs	583,305	315,013
		<b>715,371</b>	<b>484,988</b>
<b>Governance costs</b>	Independent examiner's fee	1,320	1,200
	Accounting advice & payroll services	4,655	4,139
	Trustees' expenses	-	-
	Trustee meeting	-	-
		<b>5,975</b>	<b>5,339</b>
<b>Total</b>		<b>777,946</b>	<b>563,174</b>

### 4. TANGIBLE FIXED ASSETS

	Freehold land and buildings (£)	Other land and buildings (£)	Plant, machinery and motor vehicles (£)	Fixtures, fittings and equipment (£)	Total (£)
<b>Cost</b>					
At 1 January 2022	-	-	14,608	-	14,608
Additions	-	-	-	-	-
Disposals	-	-	-	-	-
At 31 December 2021	-	-	14,608	-	14,608
<b>Depreciation</b>					
At 1 January 2022	-	-	3,754	-	3,754
Charge for the year	-	-	2,922	-	2,922
Disposals	-	-	-	-	-
At 31 December 2022	-	-	6,676	-	6,676
<b>Net Book Value</b>					
At 31 December 2022	-	-	7,932	-	7,932
At 1 January 2022	-	-	10,854	-	10,854

## 5. DEBTORS AND PREPAYMENTS

Analysis of debtors	Amounts falling due within one year (£)		Amounts falling due after more than one year (£)	
	2022	2021	2022	2021
Trade debtors	-	-	-	-
Amounts due from subsidiary and associated undertakings	13,651	3,241	-	-
Other debtors	-	-	-	-
Prepayments and accrued income	86,823	57,730	-	-
<b>Total</b>	<b>100,474</b>	<b>60,971</b>	-	-

## 6. CREDITORS AND ACCRUALS

Analysis of creditors	Amounts falling due within one year (£)		Amounts falling due after more than one year (£)	
	2022	2021	2022	2021
Loans and overdrafts	-	-	-	-
Trade creditors	-	1,200	-	-
Amounts due to subsidiary and associated undertakings	-	-	-	-
Other creditors	3,797	2,882	-	-
Accruals and deferred income	33,548	26,169	-	-
<b>Total</b>	<b>37,345</b>	<b>30,251</b>	-	-

## 7. RESTRICTED FUNDS

Fund Name	Purpose and Restrictions
<b>Skin Cancer Prevention (Restricted)</b>	Skin cancer prevention services for people with albinism in Tanzania and Malawi
<b>Research (Restricted)</b>	Research into access to health for people with albinism in Tanzania
<b>Awareness Raising (Restricted)</b>	Creating and promoting positive imagery of people with albinism in Africa to raise awareness
<b>Vision Programme (Restricted)</b>	Vision services for people with albinism in Tanzania
<b>Umoja Children Centre</b>	Building of a centre for learning and healing for children with albinism in Tanzania
<b>Malawi Operations</b>	Operational overheads for Standing Voice's team based in Lilongwe
<b>UNVFVT Victim Support)</b>	Psychosocial and material assistance for survivors of torture who have albinism in Malawi, funded by the UNVFVT

### Movement of major funds:

Fund names	Fund balances brought forward 1 January 2022 (£)	Incoming resources (£)	Outgoing resources (£)	Transfers (£)	Gains and losses (£)	Fund balances carried forward 31 December 2022 (£)
Skin Cancer Prevention Research	6,678	355,954	361,487	-	-	1,145
Awareness Raising	-	-	-	-	-	-
Vision Programme	55,058	-	4,819	-	-	50,239
Umoja Children Centre	10,612	73,453	75,264	-	-	8,801
Malawi Operations	121,360	87,500	352	-	-	208,508
UNVFVT Victim Support	2,332	23,193	24,958	-	-	567
Core Costs	5,481	33,455	38,165	-	-	771
	60,370	248,644	201,933	-	-	107,081
<b>Total Restricted Funds</b>	<b>261,891</b>	<b>822,199</b>	<b>706,978</b>	<b>-</b>	<b>-</b>	<b>377,112</b>

### 8. UNITED NATIONS VOLUNTARY FUND FOR VICTIMS OF TORTURE

Grant income	2022 (£)
P-1187-DA-22	33,455
Expenditure	2022 (£)
Salaries	13,114
Beneficiary support and training	18,928
International travel	446
National travel	372
Contribution to the Independent Examination of the charity's accounts	595
<b>Total amount (£)</b>	<b>33,455</b>

### 9. DETAILS OF CERTAIN ITEMS OF EXPENDITURE

Trustee expenses	2022 (£)	2021 (£)
Number of trustees who were paid expenses	1	1
Nature of the expenses	Bill payments	Bill payments
<b>Total amount paid (£)</b>	<b>-</b>	<b>357</b>

Fees for examination of the accounts	2022 (£)	2021 (£)
Independent examiner's or auditor's fees for reporting on the accounts	1,320	1,200
Other fees (for example: advice, consultancy, accountancy services) paid to the independent examiner or auditor	3,696	964

#### Support costs:

Support Costs Type	Fundraising activity (£)	Charitable Activity (£)	Governance Activity (£)	Total Cost (£)
Building costs	12,946	30,206	-	43,152
Communications	1,397	3,259	-	4,656
Legal & professional	964	2,249	-	3,213
Financial costs	-3,640	-8,494	-	-12,134
Depreciation	877	2,045	-	2,922
<b>Total amount (£)</b>	<b>12,544</b>	<b>29,265</b>	<b>-</b>	<b>41,809</b>

## 10. GRANT-MAKING

Grants to individuals/institutions Purpose for which grants made	31 Dec 2022 Total amount (£)	31 Dec 2021 Total amount (£)
Health services / Skin cancer prevention treatments and manufacturing of sunscreen	6,000	551
<b>Total amount (£)</b>	<b>6,000</b>	<b>551</b>

*There were no support costs associated with the charity's grant-making.*

## 11. STAFF COSTS

Staff costs	2022 (£)	2021 (£)
Gross wages, salaries and benefits in kind	136,148	167,317
Employer's National Insurance costs	7,513	9,703
Pension costs	3,196	3,343
<b>Total staff costs</b>	<b>146,857</b>	<b>180,363</b>

Average number of full-time equivalent employees in the year	2022	2021
<i>The parts of the charity in which the employees work:</i>		
Fundraising	2	2
Charitable activities	3	3
Governance	1	1
Other	-	-
<b>Total</b>	<b>6</b>	<b>6</b>

## 12. TRANSACTIONS WITH RELATED PARTIES

Name of trustee or connected party	Legal authority (e.g. order, governing document)	Amounts paid or benefit value	
		2022 (£)	2021 (£)
Harry Freeland	Governing document	45,000	45,000

*There are no amounts owing to or from the charity's trustees or other related parties by the charity at the year end. All transactions undertaken by (or on behalf of) the charity in which a trustee or related party has a material interest have been disclosed in the Notes to the Accounts.*





**STANDING VOICE**

England & Wales - Charity number 1151250

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# Accounts

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# Trustees' Annual Report and Accounts

2021



## FOREWORD

As we look back on another year, we want to thank all of our partners and supporters for their enduring commitment to Standing Voice. Our organisation has gone from strength to strength in 2021, expanding our reach across Tanzania and Malawi and introducing new initiatives to support people with albinism and their families. In the face of ongoing global uncertainty, we have been able to push forward because of the strength and commitment of our partners.

Although we continue to operate in the long shadow of the Covid-19 pandemic, we are delighted to be providing life-saving healthcare, education, livelihoods and welfare support to record numbers of people with albinism in Africa.

In partnership with the Governments of Tanzania and Malawi, we are now delivering regular dermatological healthcare to 6,435 people with albinism across both countries: building the ability of patients, caregivers and health workers to eradicate skin cancer and keep people with albinism safe from the sun. 2021 has also seen the conclusion of our groundbreaking research project on albinism and skin cancer: harnessing clinical data, this Wellcome Trust-funded project has brought together people with albinism, artists and dermatologists to explore their experiences of albinism and health through music, drama and participatory performance.

To ensure students with albinism continue to be supported throughout the pandemic, our team has been raising awareness and providing training on albinism in schools throughout Tanzania. During 2021 167 teachers have been trained to promote inclusive education and advocate for the rights of students with albinism in their care. We have also continued to provide close support for our scholarship recipients, monitoring their welfare and meeting their needs throughout this difficult time.

Covid-19 has introduced challenges, of course, but it has also created opportunities to learn and innovate. It has been necessary to maintain closer dialogue than ever with our partners and beneficiaries, in order to understand and address the rapidly evolving needs of people with albinism and their families. It is precisely for this reason that we have introduced new initiatives during the pandemic, including, in 2021, a series of workshops designed to empower mothers and protect babies impacted by albinism, as well as a formal counselling service to give people with albinism and their families a confidential platform to access psychosocial support during dermatology clinics in hospitals.

We are in awe of the people with albinism we support, who have gone above and beyond this year in their quest to overcome discrimination and claim equal participation in society. All of the groups at our Umoja Training Centre are flourishing, particularly the tailors – a group of women with albinism, producing thousands of sun-protective hats for distribution through our dermatology clinics – and the young reporters, who are reaching audiences throughout Tanzania with their radio broadcasts about life with (and beyond) albinism. We are humbled by the joyful and powerful Women's Albinism Action Group: a group of women impacted by albinism who are igniting change in their communities and equipping their peers with the tools to defend human rights.

Despite these triumphs, people with albinism throughout Africa continue to endure unimaginable human rights violations. Malawi has witnessed a string of witchcraft-related atrocities in 2021, while a person with albinism was murdered in Tanzania in May for the first time in six years. We are heartbroken by this violence, and remain more committed than ever to raising awareness and building understanding of albinism and tackling these incidents at their root. This year we have again addressed the United Nations in Geneva and implored the international community to take action. On the ground, we are working with the United Nations Voluntary Fund for Victims of Torture to protect and rehabilitate survivors, ensuring they receive the support they need, in healthcare, housing, and physical and economic security.

In July, Standing Voice was delighted to renew its long-term partnership with the Pierre Fabre Foundation and the Regional Dermatology Training Centre for a further 6.5 years. This new partnership will support the expansion of the Skin Cancer Prevention Programme to all 31 regions of Tanzania and 24 districts of Malawi by 2027, as well support the scale-up of a range of complementary holistic activities in eyecare, social protection and livelihoods training.

Like the rest of the world, we cannot be sure what 2022 will bring. But – with the ongoing commitment of our team, partners and supporters – we know that a brighter future for people with albinism in Africa can be realised. To everybody who has found the time, energy and money to support Standing Voice this year: we thank you.

*Presented by*

Sabine Zettler  
Chair of the Board of Trustees  
05/09/2022



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## LEGAL AND ADMINISTRATIVE INFORMATION

<i>Charity Name</i>	Standing Voice (UK)
<i>Charity No.</i>	No. 1151250 Charitable Incorporated Organisation (CIO)
<i>Postal Addresses</i>	Unit 34b Regent Studios 8 Andrews Road London E8 4QN  P.O. BOX 1902 Isamilo, Mwanza Tanzania
<i>Registered Addresses</i>	49 Newick Road London E5 0RP  P.O. BOX 180 Ukerewe Island, Mwanza Tanzania
<i>Board of Trustees</i>	Sabine Zetteler Gurmeet Kaur Harry Freeland Johanna Freeland
<i>Chair</i>	Sabine Zetteler
<i>Administration</i>	Harry Freeland, Jon Beale, Sam Clarke, Emily Spence, Kathrin Scholler, Rosa Shindler, Nofal Ali Pasha Supported by a growing team of dedicated volunteers



## REPORT OF THE TRUSTEES

### Constitution

Standing Voice (UK) was originally constituted under a Foundation Constitution that came into effect on 14th March 2013, on which date Standing Voice became registered as a Charitable Incorporated Organisation (CIO). The trustees are the only members of the CIO. If the CIO is wound up the members have no liability to contribute to its assets and no personal responsibility for settling its debts or liabilities.

### Board of Trustees

Trustees are appointed by existing trustees through an electoral process. There may be no fewer than three trustees at any one time on the Board of Trustees. There are four at present, and we aim to expand the Board further during 2022.

Standing Voice trustees hold quarterly board meetings. The board also addresses governance matters as and when necessary, through e-mail or other means as necessary.

Decisions are made either at a meeting of the charity trustees, or by resolution in writing or electronic form and agreed upon by all of the charity trustees. Agreements may comprise either a single document, or several documents containing the text of the resolution in like form to each of which one or more charity trustees has signified their agreement.

No decision shall be made at a trustee meeting unless a quorum is present at the time the decision is taken. The quorum is two charity trustees, or the number nearest to one third of the total number of charity trustees, whichever is greater, or such larger number as the charity trustees may decide from time to time.

In selecting trustees, consideration is given to the overall breadth of knowledge and experience required of the Board of Trustees. Candidates are typically interviewed by at least two existing trustees and nominations are then presented for approval to the board. Successful candidates, once appointed, receive appropriate training documentation about the roles and responsibilities of being a Standing Voice trustee.

Standing Voice has three active boards: Standing Voice UK (4 members), Standing Voice Malawi (4 members) and Standing Voice Tanzania (4 members).

### Advisory Board

The Standing Voice Board of Trustees is supported by an Advisory Board made up of 9 experts from 7 countries (Malawi, Tanzania, Togo, USA, UK, France and Ireland). This Board is made up of a pool of experts specialising in the fields of public health, dermatology, ophthalmology, education, trauma recovery, genetics and general surgery - all with a depth of expertise specifically on albinism.

The Advisory Board provides expert guidance to the UK Board of Trustees, to help determine strategy. The Advisory Board also works closely with UK executive management on the logistical requirements for developing programmatic interventions. This commonly includes identifying how new services should be designed and piloted; contributing to the analysis of pilot findings; guiding training and implementation of such initiatives; developing resources and identifying and applying for funding available.

Thank you to our Advisory Board members Mr Andrew Sharp, Professor Daudi Mavura, Dr Kelvin Maponda, Professor Melissa Levin, Dr Mark Wheeler, Professor Bayaki Saka, Professor Gérard Lorette, Dr Patricia Lund and Professor Charlotte Baker.

## Organisational Structure

The UK Board of Trustees manages the governance affairs of the charity on a voluntary basis and meets as necessary for this purpose, at least once a quarter. Standing Voice's Malawi and Tanzania offices report to Standing Voice UK. Therefore, the UK Board has primary governance responsibility for all Standing Voice operations. UK Trustees represent a range of fields including international development, human rights, financial management, public relations, media and the arts. The UK Board of Trustees is supported by the Advisory Board made up of experts from 7 countries in the fields of health, education, research and albinism.

The Advisory Board works closely with the UK management team to guide programmatic developments. The UK Executive Management team oversees all high level strategic decisions across Standing Voice's offices. The UK Programmes and Financial Management Team ensures that all implementation is delivered in line with organisational strategy and to the requirements of Standing Voice's funders, as well as internal and statutory financial regulations. Our UK Communications and Fundraising Team oversees the procurement of funding to sustain and grow our work, and ensure the charity maintains a high level of visibility around the world.

Our registered offices in Malawi and Tanzania are each governed by a Board of Trustees that oversees all governance matters within the context of local standards, regulations and protocols. Standing Voice maintains a breadth of expertise on each of our local Boards which include human rights and employment lawyers, human rights advocates, management experts and representatives of National Human Rights Institutions. Staff team management in each of the Standing Voice country teams is handled by the Executive Director of the Malawi and Tanzania office respectively.

Harry Freeland is Executive Director of Standing Voice UK (since April 2014) and remains on the UK Board of Trustees. During the report period the charity had 7 paid staff members in the UK supported by a committed team of volunteers. Our global team comprises an additional 19 paid staff members based in Tanzania and 5 based in Malawi, as well as international consultants.

People with albinism and their families are embedded as key decision-makers at every level of Standing Voice. As trustees and senior leaders across our UK, Tanzania and Malawi offices, people with albinism and their families are actively engaged in governance, programme design and fundraising, building and shaping a culture of accountability grounded in, and responsive to, the lived experience of our service users.

## Contributions of Volunteers

Standing Voice continues to work closely with skilled volunteers from a variety of professional and academic backgrounds who are committed to ending human rights abuses against people with albinism.

Our programmes are supported by a pool of local and international expert volunteer researchers, professors, ophthalmologists, dermatologists, geneticists and performance artists who continue to complement the development and expansion of our work through the provision of research, resource development, training, and ongoing mentorship during the report period.

Our volunteer engagement has resulted in a unique pool of expertise on albinism supporting Standing Voice's global operations. We have formalised this provision of expertise through the establishment of advisory boards, which play a vital role in supporting our country Boards of Trustees and staff teams.

We are extremely grateful to all of our volunteers who continued to inform and shape our life-saving programmes this year.

## Our Purpose and Objectives

Standing Voice is an international NGO working in Tanzania and Malawi, with its headquarters in the United Kingdom. Standing Voice's primary objective is to improve the quality of life of people with albinism in Africa.

The objectives of the CIO are:

- I. the advancement of education;*
- II. the advancement of mental and physical health and the saving of lives;*
- III. the relief of poverty and the improvement of the conditions of life in socially and economically disadvantaged communities;*
- IV. the promotion of human rights and the promotion of equality and diversity, in particular but without limitation so as to relieve the needs of people who are socially excluded by assisting them to integrate into society.*

For the purposes of the above:

*I. "human rights" means human rights as defined in the Universal Declaration of Human Rights and subsequent United Nations conventions and declarations and will be promoted in particular by education about human rights and promoting respect for human rights;*

*II. people who are "socially excluded" means people who are excluded from society, or parts of society, as a result of one or more of the following factors: financial hardship; youth or old age; ill health (physical or mental); disability or medical condition; discrimination on the grounds of sex, race, ethnic origin, religion, colour, creed or sexuality; poor education or skills attainment.*

Standing Voice exists as a catalyst to amplify the voices of others. We aim to empower the people we work with to be the agents of change in their own lives, to build resilience and be healthy and self-sufficient. We currently focus on promoting the social inclusion of people with albinism in Tanzania and Malawi. Our team has over 14 years' experience working with this group. We are currently planning further expansion to other countries in Sub-Saharan Africa, through the replication of our programme models in collaboration with key partners.

People with albinism are commonly the victims of social exclusion in Sub-Saharan Africa, which has led to witchcraft-fuelled murder and marginalisation from health and education services. Our work with this group centres around several programmatic areas: Skin Cancer Prevention, Vision and Education, Trauma Recovery, Economic Empowerment and Advocacy. Through our core programmes our support is holistic and comprehensive to reflect the complex needs of people with albinism in their local context. We achieve our objectives by collaborating with a network of local stakeholders (such as government bodies, local community groups and international NGOs). All of our initiatives promote the social inclusion of people with albinism by:

- I. Advancing understanding and knowledge about albinism in wider society*
- II. Advocating for progressive state action*
- III. Developing the skills and expertise of both people with albinism and wider community members*
- IV. Increasing the positive impact of local service providers*
- V. Promoting the positive impact of local non-governmental stakeholders (civil society)*

The trustees of Standing Voice declare that they have had regard to both the Charity Commission guidance on public benefit and section 17(5) of the Charities Act 2011 on public benefit in carrying out their duties to achieve the charity's objectives.



## Principal Activities

Broadly, Standing Voice works across five thematic areas: Skin Cancer Prevention, Ophthalmology and Education, Economic Empowerment, Trauma Recovery and Advocacy. We have made significant advances in each of these areas throughout 2021.

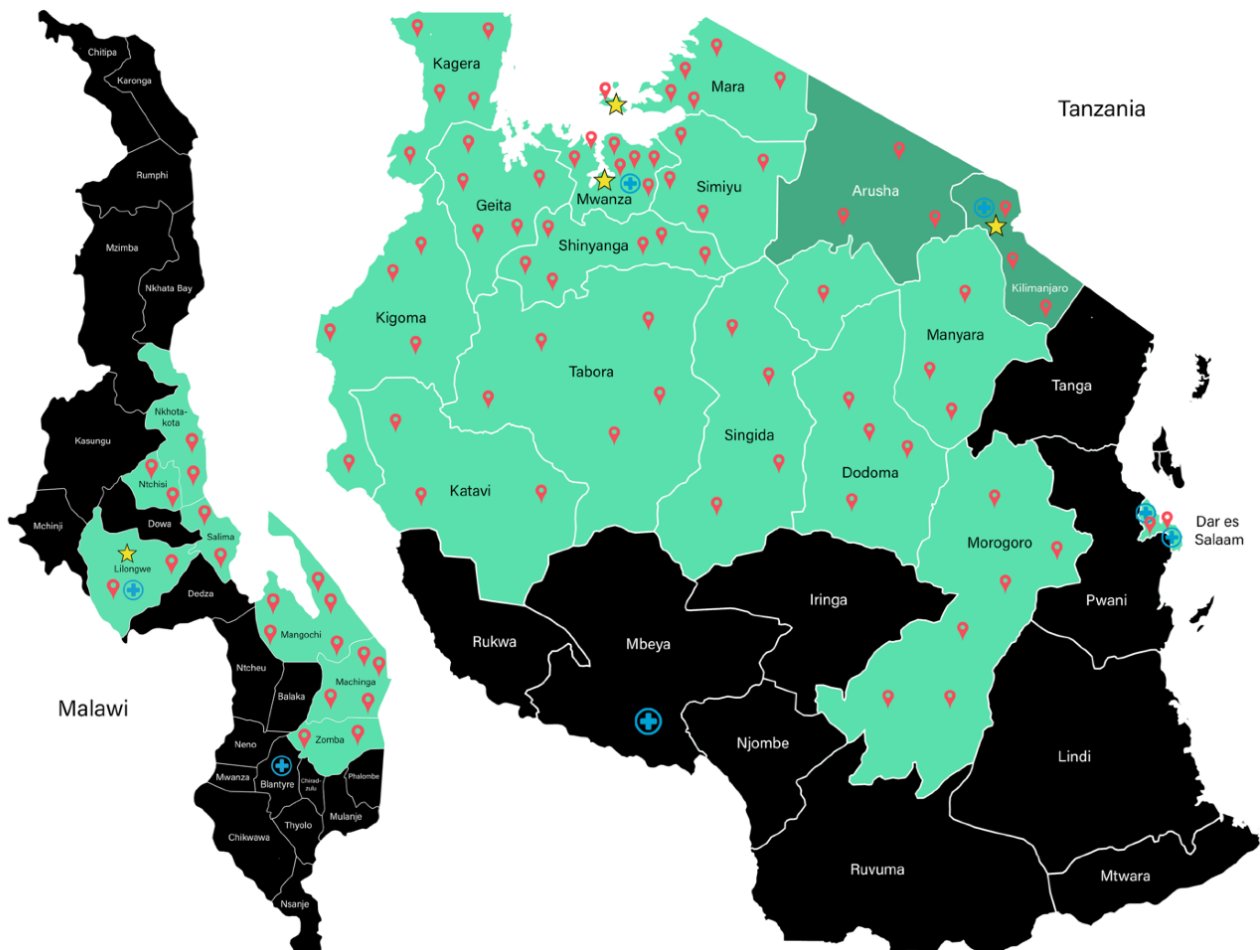
### SKIN CANCER PREVENTION

In collaboration with the Ministry of Health our Skin Cancer Prevention Programme (SCPP) trains dermatologists to deliver health information and treatment to thousands of people with albinism across Tanzania and Malawi. Clinics are held in hospitals and health centres, and provide patients with skin cancer screening; liquid nitrogen cryotherapy; health education; sun-protective clothing; surgery referral where necessary; and a regular supply of sunscreen. The programme has been endorsed by the United Nations as a model of best practice and is the largest Skin Cancer Prevention programme for persons with albinism in Africa today. In Tanzania we have seen reduced cancer prevalence by as much as 85% in locations where the SCPP has operated longest. By the end of 2021, the SCPP had formally enrolled 6,063 people with albinism across 15 regions of Tanzania and 7 districts of Malawi (thousands more have been reached through sunscreen distribution and health education only, and are accordingly excluded from this total).

#### SCPP Operations

December 2021

- Regions accessing full SCPP service
- Regions currently not served
- ⊕ Referral Hospitals
- Regions with services and DVO training sites coordinated by the RDTC
- ★ Standing Voice and RDTC Offices
- 📍 Clinic locations



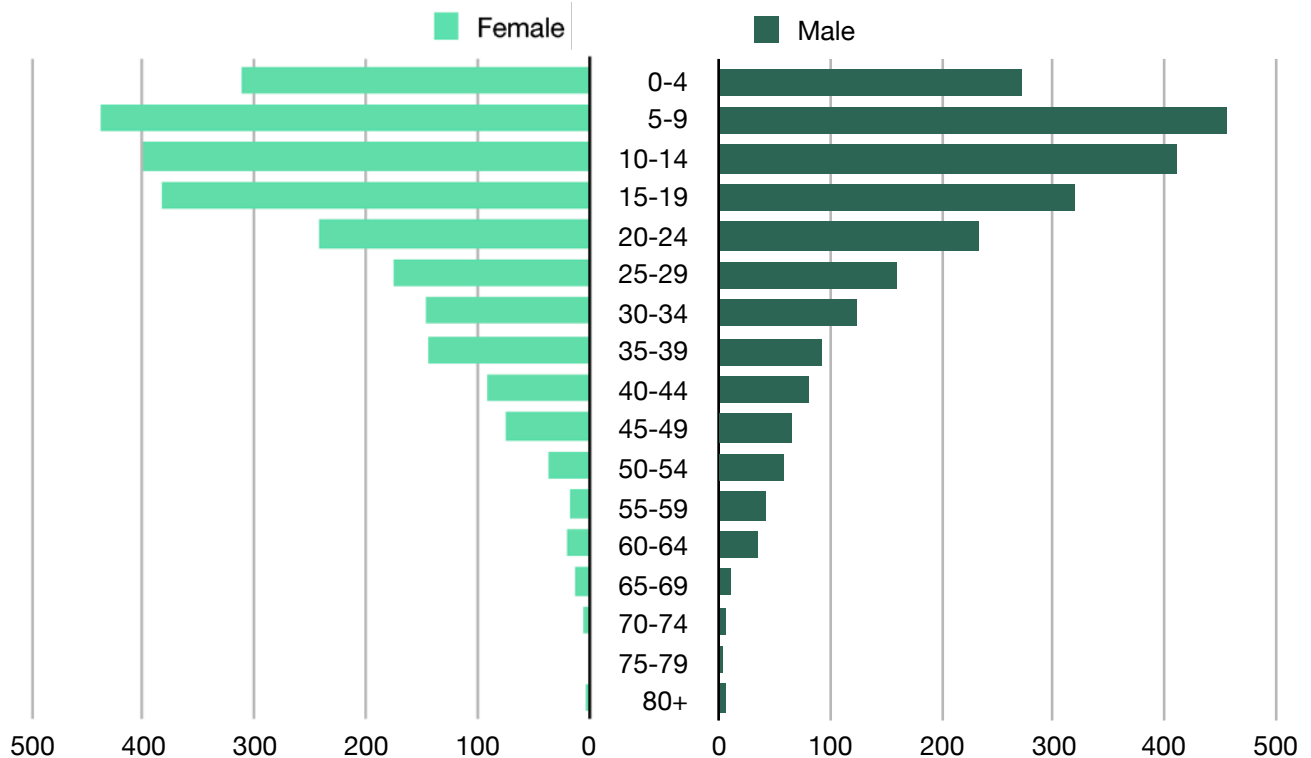
In Tanzania, we saw 1,749 new patients in 2021 (a growth rate of 53.1% from 2020). Annually, we saw a 49.4% increase in registered male patients and a 56.8% increase in registered female patients. Our fastest-growing regions were Dodoma (29.2%), Katavi (27.7%) and Tabora (26.6%), while our slowest-growing were Mwanza (9.6%) and Shinyanga (8.7%), which are also the regions with the highest numbers of registered patients and where the SCPP has been operating longest.

In Malawi, we saw 287 new patients across the entire year (a growth rate of 39.2% from 2020). Annually, we saw a 44.7% increase in registered male patients and a 34.4% increase in registered female patients. Our fastest-growing district was Machinga (11.3%), with Nkhotakota our slowest (5.5%).

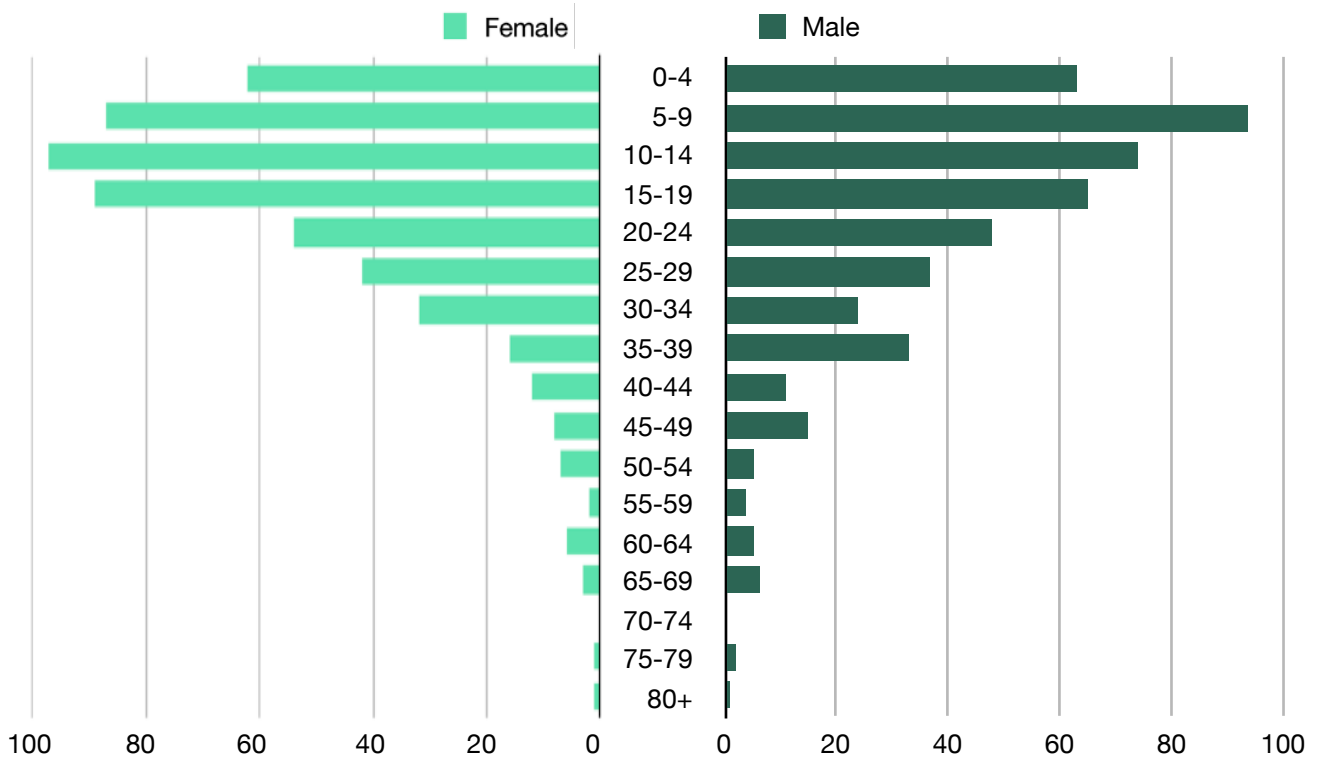
Across both countries, we registered 2,036 new patients in 2021, reflecting a combined annual growth rate of 50.5%. 113 SCPP clinics were delivered across Tanzania and Malawi during 2021.

We are encouraged to see continued gender parity in our patient population, with women and men respectively comprising 51.3% and 48.7% of our patients in Tanzania and 51.8% and 48.2% of our patients in Malawi. Younger age brackets continue to dominate our patient population in a manner that is consistent with the age distribution of the general population in both Tanzania and Malawi. In Tanzania, our average patient age is 20 and 61.3% of patients are aged 19 or below; in Malawi, the average age is 19 and 62.7% of patients are aged 19 or below. The population pyramids below demonstrate particularly strong mobilisation of patients aged 5-19 in both Tanzania and Malawi.

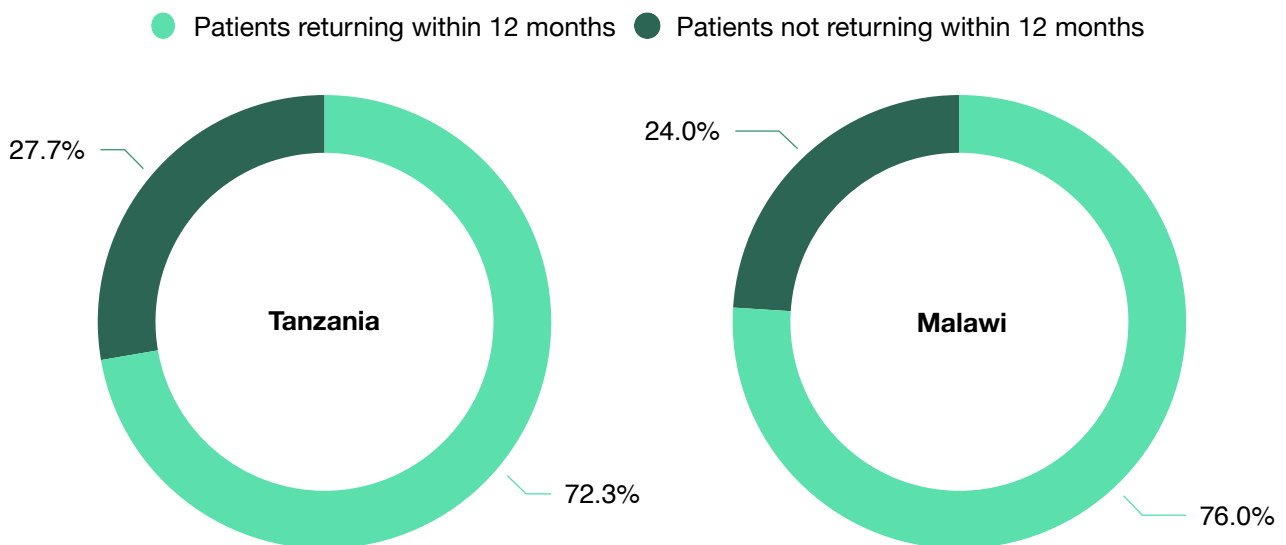
**Distribution of Registered Patients in Tanzania**



### Distribution of Registered Patients in Malawi



In Tanzania, we saw 4,132 patients throughout 2021. Of these, 2,383 patients were returning within 12 months (representing an annual retention rate of 72.3%). In Malawi the picture was similar: in 2021 we saw 843 patients, of whom 557 were returning within 12 months (an annual retention rate of 76.0%). Across both countries in 2021 we saw 4,975 patients, of whom 2,940 were returning within 12 months (a combined annual retention rate of 73.0%).





In 2021, 237 patients were referred by Dermatologists in the SCPP to a major hospital for further treatment. This included 160 patients in Tanzania and 77 patients in Malawi. In both countries, the average age of patients referred was 35 years old: noticeably older than the average age of all registered patients, which is 20 in Tanzania and 19 in Malawi. This is logical, given that older patients are more likely to have previously incurred sun-related skin damage, and have had more time for skin cancer and other malignant skin conditions to develop. Approximate gender parity was observed among referred patients in both Tanzania and Malawi.

We distributed thousands of sun-protective items in Tanzania and Malawi during 2021. In the last six months of the year alone, we distributed 19,405 jars of sunscreen, 5,980 sun-protective wide brimmed hats, 241 sunglasses, 326 umbrellas for mothers of babies with albinism and 5342 educational booklets on albinism.

We have been delighted to see continued development in the capacity of a tailoring group we have supported at our Umoja Training Centre on Ukerewe Island since 2015. The Tunajitambua Tailors – a collective of mostly women, with and without albinism – produced a total of 2,430 wide brimmed hats between July and December 2021, which were then distributed to people with albinism through SCPP clinics in Tanzania. Hat production will be scaled up significantly during 2022.

During this reporting period, we produced a French version of our Skin Cancer Prevention Manual of Best Practice. The existing English version of the manual was translated into French and proofread by a network of medical experts in France. 500 copies of the French version will be distributed across six Francophone African countries in 2022: Mali, Burkina Faso, Togo, Ivory Coast, Niger and the DRC. The English version has also been updated and re-printed, and will be distributed in six Anglophone African countries: Tanzania, Malawi, Zimbabwe, Uganda, Kenya and Rwanda. A total of 1,000 copies of the Manual of Best Practice will be distributed to training institutions, consultant dermatologists, dermatology officers and clinicians across these 12 countries.

This year we have continued to provide training for a range of stakeholders to strengthen the dermatological health of people with albinism in Tanzania and Malawi. Throughout the year we have delivered comprehensive training to 46 health professionals and 97 community advocates (Social welfare officers, Health Surveillance Assistants and Albinism Association leaders), while providing albinism sensitisation for 8162 patients and their families across 417 sessions.

In July Standing Voice was delighted to have renewed its long-term partnership with the Pierre Fabre Foundation and the Regional Dermatology Training Centre for a further 6.5 years. This new partnership will support the expansion of the Skin Cancer Prevention Programme to all 31 regions of Tanzania and 24 districts of Malawi by 2027, as well support the scale-up of a range of complimentary holistic activities in eyecare, social protection and livelihoods training.

Standing Voice remains committed to expanding the Skin Cancer Prevention Programme internationally, to bring high-quality dermatological healthcare to people with albinism across Africa. With the continued support of our patients and partners, we will work hard to realise this ambition in the months and years ahead.

## VISION & EDUCATION

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In many African countries, the low vision that people with albinism experience as a result of their melanin deficiency is widely misunderstood and rarely accommodated by health and education providers. This damages the participation and performance of many children with albinism in school, and restricts opportunities for professional development and income generation among many adults with albinism.

Since 2014, Standing Voice has partnered with the Government of Tanzania to establish a nationwide network of clinics providing vision care and education to 3,882 people with albinism across 9 regions of Tanzania. We target schools to improve educational performance and promote inclusive teaching practice, and have trained hundreds of teachers as 'Vision Ambassadors' tasked with promoting the rights of students with albinism in schools.

Throughout 2021, we have continued to strengthen the quality and sustainability of the Vision Programme by training teachers to understand and address the needs of students with albinism in schools. Many students with albinism in Tanzania underperform academically and grow up to be unskilled, unemployed and trapped in a structural cycle of poverty. By training teachers to nurture success and confidence among students with albinism at an early age, support networks are created for previously isolated individuals, creating role models and reversing stigma to ensure long-term integration and improved socio-economic security. This year, we trained 167 teachers across 15 schools in four regions of Tanzania.

This year has also been spent making important qualitative developments to the Vision Programme, including integrating all ophthalmological data into our new patient database, and renewing partnerships to procure assistive vision devices for distribution to patients in 2022. In January next year we will begin the start of a new partnership with long-term donor Essilor Vision For Life, which will see our Vision Programme expand to new regions of Tanzania to reach underserved populations of people with albinism with comprehensive eye care.

Alongside our teacher training and school outreach in 2021, Standing Voice has also provided particularly close support for beneficiaries of our Education Scholarship Programme, which sponsors children and young adults with albinism to study at inclusive and high-achieving schools and universities.



## TRAUMA RECOVERY

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In Malawi, 2021 has seen the continuation and expansion of Standing Voice's trauma rehabilitation initiative for people with albinism. Funded by the United Nations Voluntary Fund for Victims of Torture, the project provides tailored material assistance to people with albinism who have survived physical and psychological violence in Malawi. Following an extensive mapping exercise and series of needs assessments in 2020, this year our team has continued rolling out comprehensive tailored support packages for people with albinism and their families impacted by torture. Support has included housing and home security measures, micro-finance and livelihood support, medical or school supplies, facilitation of trauma recovery and family reconciliation, and direct advocacy interventions in situations of risk, conflict or exclusion. The project is currently supporting 31 beneficiaries impacted by torture, including child survivors of attack as young as 7.

2021 also saw the continued development of our First Response Teams (FRTs) in Tanzania and Malawi, designed to rapidly bolster a trained support network available to survivors of attack. Comprising social welfare professionals and individuals with first-hand experience of albinism-related stigma, the FRTs have spent the last year undergoing a programme of specialist training as part of a project funded by the United Nations Voluntary Fund for Victims of Torture with Mark Fish, a world-leading expert in trauma recovery who has innovated an effective model for community-based therapy suitable for delivery by community stakeholders and mental health professionals. This training has involved one intensive workshop event held in Lilongwe complimented by multiple online training events in 2021, representing the first intervention of this nature spanning Tanzania and Malawi, and specifically designed around the trauma recovery needs of people with albinism. The training of the FRT will continue into 2022 and focuses on individual and group counselling techniques that can be deployed in a wide range of scenarios. FRT members have been exercising these learnings through their ongoing work and support relationships with survivors of attack who have albinism in Malawi across multiple districts which our team defines as 'high risk' for people with albinism based on the available attack data.

In addition members of the FRTs have been operating an albinism helpline in Tanzania and Malawi, and have been analysing call data to develop awareness of our beneficiaries' emerging needs. To use our Malawi helpline as an example, 15% of calls in 2021 related to food security and 20% related to security threats. Security threat reports included reports of attempted abductions. This is a strong demonstration of the life threatening needs of people with albinism in Malawi who are experiencing high levels of risk in everyday life. The FRT responded to these needs in 2021 with law enforcement engagement; home security measures including security lighting and home reinforcements; family and community sensitization; individual counselling; and provision of farming supplies and food.

In addition, the FRT is involved in promoting access to justice in high profile murder cases. This has included the continuation of FRT follow up and police assistance in the murder case of a 22 year old man in Machinga District. The FRT also enrolled a key witness to the murder in our tailored support initiative for survivors of torture. The FRT has conducted community awareness in the community where this murder occurred.

This year, we also piloted the delivery of psychosocial counselling sessions at SCPP clinics in four districts of Simiyu, Tanzania. These sessions were delivered by a member of the Tanzania FRT as well as members of the Women's Albinism Action Group (WAAG), a women-led action group supported by Standing Voice and guided by the FRT to provide psychosocial support to people with albinism. This intervention accelerated the capacity development of WAAG members and enabled wider provision of psychosocial support to patients.



## ECONOMIC EMPOWERMENT

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Economic security and access to livelihoods are a pivotal (and often overlooked) challenge facing people with albinism. Stigma and discrimination—exacerbated by high rates of skin cancer, and neglected vision needs in classrooms and workplaces—deprive many people with albinism of income-generating opportunities and pathways of professional development.

In 2013, SV built and founded the Umoja Training Centre (UTC): a facility providing formal training initiatives, tailored support for victims of trauma, to promote improved well-being, integration and shared prosperity for people with albinism and their families on Ukerewe Island on Lake Victoria Tanzania.

The UTC is a hub of community integration and a centre of healing for vulnerable people with albinism who have experienced discrimination and violence. Today the UTC delivers vocational training in a range of disciplines including tailoring, photography, radio production, storytelling and performance, print-making, batik, soap-making and art. As well as a range of tailored support initiatives such as group therapy, women's support groups and community outreach for persons with albinism. It also operates a community library and English lessons to facilitate the integration of people with albinism into wider society.

2021 has seen the UTC community groups achieve significant progress by honing their skills, marketing their products, and generating income. The 'Tunajitambua Tailors' group have reported significant changes in their lives as a result of their increased income and all-round improved wellbeing. Members have been able to build new and more secure homes, and are now able to provide for their families from the income they are generating. The group produced 2,430 wide-brimmed hats for distribution through SPPP clinics during 2021. The soap-making group has similarly produced handmade soap, which is being sold directly to the Ukerewe community in markets and from the UTC. The Young Reporters Group continues to broadcast radio programmes across local stations, airing their voices to thousands of people in the Lake Zone of Tanzania. The Tanzania Albinism Collective music group has recorded their second album and successfully released two new music videos during 2021.

For three years, the UTC Community Library has brought together all parts of the community through their love of reading including children and adults, students and teachers, farmers, community activists, entrepreneurs, local leaders and Government officials.

In 2022 we will begin replicating the successful model of the UTC through a new centre we are building on mainland Tanzania.



## ADVOCACY AND RESEARCH

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Standing Voice creates platforms for people with albinism to speak out against violence and assert their own rights. We advocate locally and globally for the welfare of people with albinism through documentary films, academic publications, interdisciplinary symposia and stakeholder consultations. Our organisation has special consultative status with the United Nations Economic and Social Council, with annual accreditation to attend and participate in a wide programme of human rights events at UN headquarters in both Geneva and New York.

Despite lingering international travel challenges resulting from the Covid-19 pandemic, in 2021 we have continued to advocate for the rights of people with albinism on the global stage. In March, we delivered a remote video intervention to the 46th Session of the United Nations Human Rights Council in Geneva, calling attention to the escalation of violence against people with albinism in Malawi and imploring the international community to take action. In June, we joined with albinism advocates and organisations around the world in a virtual commemoration of International Albinism Awareness Day (IAAD). Our teams also took part in national IAAD celebrations in Dar es Salaam in Tanzania and Nkhoswezi in Malawi, marking IAAD 2021 alongside Govts, albinism associations and Civil Society. This year we are provided free skin and eye screenings for all people with albinism who attended.

This year also saw the conclusion of our research project 'Understanding Albinism and Skin Cancer in Tanzania' funded by the Wellcome Trust. The project provided an opportunity for people with albinism to interact with key findings from the Skin Cancer Prevention Programme (SCPP) and sought to build those individuals' ability to influence the implementation of skin cancer prevention and advocacy efforts using the information with which they had been provided. The participant group consisted of 22 persons with albinism, who had mixed engagement with the SCPP, who were brought together with performance arts and health specialists through workshops and performances. Our 22 people with albinism participating were provided with selected health data from the programme, and over the course of 3 training and performance events on Ukerewe Island developed artistic responses to that information. These responses were communicated to wider stakeholders through theatrical plays, dance, music, and fine art. The project team conducted regular focus group discussions with participants throughout the project to capture real-time developments in participants' perception of their own agency as patients and the roles of service providers in protecting their welfare. The project was conducted in collaboration with the Bagamoyo Creative Arts Institute, and Regional Dermatology Training Centre (RDTC) in Moshi. We look forward to publishing project findings in an open-access journal in 2022, and continuing to leverage the insights of participatory research to shape organisational strategy more widely in future.

## DATA MANAGEMENT

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2021 saw the piloting (Jan-July) and roll out (July-Dec) of our new online data collection system in all regions and districts of Tanzania and Malawi where the SCPP is operating.

Throughout the year our teams in Malawi and Tanzania dedicated a significant amount of time to developing this new system, working closely with a group of experts from our Advisory Board.

In both countries, we delivered a series of comprehensive classroom-based training workshops to 17 SV staff and 58 health professionals responsible for rolling out the new electronic database system across clinic sites in both countries. Health professionals included Dermatologists, Dermato-Venereology Officers and Clinical Officers.

During the pilot phase feedback from doctors, staff and patients was overwhelmingly positive. All parties reported that registration and examination of patients was much more efficient with the new system, easing the pressure on the team and reducing waiting times for patients attending our clinics.

According to Bob Kumbweza, a Dermato-Venereology Officer from Mangochi, Malawi:

*“CommCare is a big step forward in how we collect data on our patients. As opposed to the old paper based approach, using CommCare saves on time that was previously used writing down registration and clinical information. It's now easier to keep patients' historical records orderly which we can refer to before and after each clinic. If we see a lesion, we can take a picture instantly and these are kept together with their records, which makes it easy for us to follow up.”*

Following the successful pilot phase, the new system was formally rolled out across all SCPP clinic sites in Tanzania and Malawi in July 2021.

In 2022 the new system will be piloted and rolled out across Ophthalmology and Social Protection programmes.



## FUNDING MATTERS

### GRANT-MAKING POLICY

The charity's policy is to make grants to collaborating organisations who are in need of funds to deliver a service in partnership with Standing Voice. On occasion the trustees may decide to give a grant to a beneficiary organisation that is not working in partnership with Standing Voice, but is working towards a shared objective of the charity.

In line with our current activities the organisation or service funded must promote the wellbeing and social inclusion of people with albinism in Africa through advancing health, education or community-based services.

All grants are awarded on the condition of robust accounting and financial reporting standards being adhered to by grant recipients.

### FUNDRAISING ACTIVITIES IN THE UK

Standing Voice applies for grants from trust funds, grant-giving foundations and institutions, and corporate donors. Standing Voice also raises funds donated by individuals reached through direct approaches and by holding planned fundraising events and campaigns.

The charity's principal sources of funding during the year have consisted of grant funders and a group of committed philanthropists donating to specific projects. Our plans for sponsored events have remained restricted during 2021 due to Covid-19.

We are proud to be funded by some of the most innovative grant funders who are active today including the Pierre Fabre Foundation, the Wellcome Trust, the International Foundation for Dermatology (IFD), the International League of Dermatological Societies (ILDS), the United Nations Voluntary Fund for Victims of Torture (UNVFVT), Essilor Vision for Life, the Sir Halley Stewart Trust, the British and Foreign School Society (BFSS), the John Armitage Charitable Trust, the Friends of Malawi Association, Esther Ireland, the Evan Cornish Foundation, the Souter Charitable Trust, and many others including those who wish to remain anonymous.

The trustees extend their sincere gratitude to all individuals and grant-givers who have donated to the organisation this year to ensure we continue our vital work.

### FINANCIAL PERFORMANCE

Income during the period 1st January 2021 to 31st December 2021 amounted to £446,643 (January 2020 to December 2020: £498,154). Voluntary income was £446,615 (2020: £498,024). Of the total income, £418,022 (2020: £431,947) was restricted and £28,593 (2020: £66,207) unrestricted. The restricted income consists of donated funds from grant funders and individuals. £261,891 (2020: £356,148) of restricted funding was carried forward. Unrestricted income was mainly from individual donations.

Expenditure amounted to 563,174 (2020: £487,778) of which £484,988 was project expenditure (2020: £423,206), £72,847 was fundraising expenditure (2020: £62,408) and £5,339 was governance costs (2020:

£2,164). Of the total expenditure, £512,279 was restricted expenditure (2020: £414,731) and £50,895 was unrestricted expenditure (2020: £73,047).

Standing Voice exercises a policy of setting aside 6 months of administration salaries and expenses as reserves to cover core costs in the event of the organisation encountering a period of reduced income. At the end of the financial year ending 31st December 2021 the charity carried forward a balance of £303,465 (2020: £419,996), and the organisation awaited funding responses from major grant funders. The trustees deemed reserve funds held to be sufficient, keeping in consideration the status of funding negotiations with key funders and the imminent disbursement of funds from donors in January amounting to over £270,000.

## **EXPENDITURE SUPPORTING KEY OBJECTIVES**

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Standing Voice has been able to increase expenditure on frontline interventions in 2021, directly increasing the wellbeing and social inclusion of people with albinism in Malawi and Tanzania. This has been vital at a time when our beneficiaries' needs are more severe than ever due to global economic conditions, societal impacts of COVID-19 and the sustained threat of attack against people with albinism. This increase in project expenditure (a £65,670 increase on 2020) has been carefully planned and deemed viable based on securing multi-year funding partnerships in 2021, which have resulted in a higher degree of cash flow security moving into 2022. Expenditure on our projects promoting the wellbeing and social inclusion of this marginalised group is consistent with Standing Voice's objectives as defined in its governing constitution.

People with albinism in Tanzania and Malawi continue to benefit from capacity development; improved dermatological and ophthalmological health services; innovative trauma recovery interventions; increased access to education; and major advances in local and international awareness on albinism resulting from Standing Voice's project activity. Additionally, through training and coordination of health, social care and education service providers in 2021 we are proud to be building a sustained, locally driven response to this issue in both countries.

The charity's projects this year have grown substantially both in terms of geographical reach, and depth of the interventions we are offering across both countries of operation. Whilst growing the footprint of its work Standing Voice is progressively interlinking services, to ensure individual projects act as support gateways for other holistic interventions provided, such as counselling for torture survivors funded by the United Nations Voluntary Fund for Victims of Torture. Scaling up geographical reach alongside investing in a holistic approach to our work has led Standing Voice to achieve its objective of ending human rights abuses against people with albinism by advancing their integration in society in 2021.



## GOVERNANCE AND RISK

### FUTURE PLANS OF THE CHARITY

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In 2022, we will expand the geographical reach of our Skin Cancer Prevention Programme in both Tanzania and Malawi. We will accelerate further our training of community leaders, teachers, health professionals, people with albinism and their families. Our work to build the capacity of our beneficiaries will also develop through increasing these individuals' access to information on their own welfare, and providing opportunities for them to communicate their own perspectives to key stakeholders who influence welfare outcomes.

Through our renewed partnership with Pierre Fabre Foundation we will also continue adapting our dermatology services to allow for the inclusion of complimentary support at dermatology clinics, specifically psychosocial support and counselling, co-funded by the United Nations Voluntary Fund for Victims of Torture. We will continue the pilot phase and launching of clinic counselling stations, deployed alongside dermatology services in 2 regions of Tanzania and 2 districts in Malawi by the end of 2022. This will involve the continued training of a team of 'first responders' equipped to provide such services in Malawi and Tanzania (our First Response Team). This team is led by Standing Voice staff members but also includes other community stakeholders such as mothers of children with albinism, teachers, social workers and civil society leaders. This intervention shall continue to involve one-to-one and family counselling support alongside material assistance for beneficiaries who are highly vulnerable. Members of our First Response Team (FRT) will also continue to strengthen our albinism helpline in both countries, building our capacity to receive and respond to a greater volume of calls by the end of the year.

By the end of 2022, the SCPP will be active in 17 regions of Tanzania and 12 districts of Malawi.

In Tanzania, we will deliver five large eye clinics, and provide teacher training in 15 schools to approximately 150 teachers by the end of 2022. In Malawi, we aim to hold a series of training workshops for Optometrists, and pilot our first eye clinic in the country before the end of 2022.

During 2022 the expansion of our work in Malawi and Tanzania, both in terms of geographic scope and impact, will be combined with our sustained efforts to continue catalysing action from national governments. We will achieve this through our advocacy work within and beyond these countries of operation, and through our position as Chair of the National Action Plan on Albinism in Tanzania.

Beyond the borders of Tanzania and Malawi we will begin supporting projects in Rwanda, and deliver training for dermatologists in Zimbabwe.

We will distribute 1,000 copies of our Manual of Best Practice: Skin Cancer Prevention and Management for Persons with Albinism in Sub-Saharan Africa to training institutions, consultant dermatologists, dermatology officers and clinicians across 12 countries in Africa during 2022 (Mali, Burkina Faso, Togo, Ivory Coast, Niger, DRC, Tanzania, Malawi, Zimbabwe, Uganda, Kenya and Rwanda). We expect a total of 920 dermatology professionals to receive the manual, driving improvements in clinical practice and enabling the delivery of more effective dermatological care for people with albinism in Sub-Saharan Africa.

## RISK

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The primary risk to the charity (and by association its beneficiaries) is currently that of insufficient funding to meet the growing needs of our beneficiary population. As our services increase in scope and depth we are continually further evidencing the complexity of people with albinism's life challenges and threats to their welfare. Meeting these challenges demands a scaled up investment of resources, to ensure our team can train a wider range of stakeholders; and increase the number of stakeholders receiving trainings (i.e health worker and community advocate training); develop the knowledge base and specialist capacity of our team; and provide more comprehensive support to individuals with the highest level of need (i.e. survivors of attack or those experiencing a continued threat). All of this, alongside the need to scale up our geographical reach in the absence of any other entity equipped to do this effectively, in terms of expertise and logistical experience.

We manage this risk through maintaining a varied portfolio of benefactor relationships, and the regular submission of new grant applications, combined with regular scrutiny of our expenditure pipeline. In 2021 our team focused heavily on securing multi-year funding partnerships, which was a successful endeavour. This has enabled us to project committed income up to 2027, significantly mitigating the risk of funding not being sufficient to meet our objectives. The board holds regular financial planning discussions to assess the financial health of the organisation and plan accordingly. The Board assesses the viability of programmatic action for the year considering both financial viability and Value for Money principles ('economy, efficiency and effectiveness').

Additionally, Standing Voice consistently manages the risk of maladministration at the point of implementation through routine monitoring of our in-country teams in Tanzania and Malawi. Regular scheduled finance and activity reports are scrutinised upon submission from these implementation teams, as a prerequisite for further fund disbursement by Standing Voice UK. Executive Management also monitors the flow of funds from the UK to our country offices through a two-step forex approval system, which ensures that any transfer between the UK and Malawi or Tanzania is reviewed and approved by two predetermined forex administrators at Standing Voice UK. Additionally, our UK trustees and management regularly visit Standing Voice local offices, partners and project sites to maintain visibility of all aspects of local operation including potential risks that require new mitigation strategies.

## RESPONSIBILITIES OF THE BOARD OF TRUSTEES

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The Trustees are responsible for managing the affairs of the CIO and may for that purpose exercise all the powers of the CIO. It is the duty of each charity trustee:

- A. *to exercise his or her powers and to perform his or her functions in his or her capacity as a trustee of the CIO in the way he or she decides in good faith would be most likely to further the purposes of the CIO; and*

*B. to exercise, in the performance of those functions, such care and skill as is reasonable in the circumstances having regard in particular to*

- i) any special knowledge or experience that he or she has or holds himself or herself out as having; and,*
- ii) if he or she acts as a charity trustee of the CIO in the course of a business or profession, to any special knowledge or experience that it is reasonable to expect of a person acting in the course of that kind of business or profession.*

The Board of Trustees are responsible for complying with the requirements of the Charities Act 2011 with regard to the keeping of accounting records, to the preparation and scrutiny of statements of account, and to the preparation of annual reports and returns for submission to the Charity Commission.

## **PUBLIC BENEFIT**

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In accordance with section 17 of the Charities Act 2011 the Trustees confirm that they have had regard to the Charity Commission's guidance in relation to public benefit. The Trustees have referred to the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning the charity's future activities. In particular, the Trustees have considered how planned activities will contribute to the aims and objectives they have set.

## **TRUSTEES' DECLARATION**

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So far as the Trustees are aware, there is no relevant information of which the charity independent examiner is unaware, and each Trustee has taken all the steps that he/she ought to have taken as a Trustee in order to make himself/herself aware of any relevant audit information and to establish that the charity's independent examiner is aware of that information.

Approved by the Board of Trustees and signed on its behalf by:

A handwritten signature in black ink, appearing to read 'Sabine Zetteler'.

**Sabine Zetteler**

Chair of the Board of Trustees

05/09/2022



## ACCOUNTS

### Independent Examiner's Report to the Trustees of Standing Voice

I report on the accounts of the charitable company for the year to 31 December 2021 which are set out on the following pages.

#### Respective responsibilities of trustees and examiner

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 114(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a member of the Institute of Financial Accountants.

Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 145 of the 2011 Act;
- follow the procedure laid down in the General Directions given by the Charities Commission under section 145 (5)(b) of the 2011 Act; and
- state whether particular matters have come to my attention.

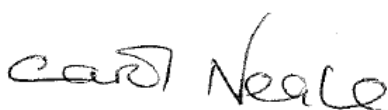
#### Basis of independent examiner's report

My examination was carried out in accordance with the general directions given by the Charities Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

#### Independent examiner's statement

In connection with my examination, no matter has come to my attention;

- 1) which gives me reasonable cause to believe that in any material respect the requirements:
  - to keep accounting records in accordance with the section 386 of the Companies Act 2016; and
  - to prepare accounts which accord with the accounting records comply with the accounting requirements of section 396 of the Companies Act 2016 and with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities (revised 2015) have not been met; or
- 2) to which, in my opinion, attention should be drawn to enable a proper understanding of the accounts to be reached.



**Carol Neale AFA MIPA**  
GS Verde Accountants  
Maple House  
Cleeve  
Bristol  
BS49 4FS

## Statement of Financial Activities (SoFA)

Statement of Financial Activities (Incorporating an Income and Expenditure Account) for the period ended 31 December 2021:

	Notes	Unrestricted funds (£)	Restricted income funds (£)	Total 2021 (£)	Total 2020 (£)
<b>Income and endowments from:</b>					
Donations and legacies		28,593	418,022	446,615	498,024
Other trading activities		-	-	-	-
Income from investments		28	-	28	130
Income from charitable activities		-	-	-	-
Other income		-	-	-	-
<b>Total income and endowments</b>	<b>2</b>	<b>28,621</b>	<b>418,022</b>	<b>446,643</b>	<b>498,154</b>
<b>Expenditure on:</b>					
Raising funds		7,699	65,148	72,847	62,408
Charitable activities		37,857	447,131	484,988	423,206
Other expenditure		5,339	-	5,339	2,164
<b>Total expenditure</b>	<b>3</b>	<b>50,895</b>	<b>512,279</b>	<b>563,174</b>	<b>487,778</b>
<b>Net income/(expenditure) and net movement in funds for the year</b>		<b>-22,274</b>	<b>-94,257</b>	<b>-116,531</b>	<b>10,376</b>
<b>Net income/(expenditure) before other recognised gains/(losses)</b>		<b>-22,274</b>	<b>-94,257</b>	<b>-116,531</b>	<b>10,376</b>
<b>Other recognised gains/(losses)</b>					
Gains and losses on revaluation of fixed assets for charity's own use		-	-	-	-
Gains and losses on investment assets		-	-	-	-
<b>Net income/(expenditure) and movement in funds for the year</b>		<b>-22,274</b>	<b>-94,257</b>	<b>-116,531</b>	<b>10,376</b>
<b>Total funds brought forward</b>		<b>63,848</b>	<b>356,148</b>	<b>419,996</b>	<b>409,620</b>
<b>Total funds carried forward</b>		<b>41,574</b>	<b>261,891</b>	<b>303,465</b>	<b>419,996</b>

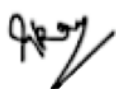
The Statement of Financial Activities includes all gains and losses recognised in the year. All the activities derive from continuing operations during the above periods.

## BALANCE SHEET

Balance Sheet as at 31 December 2021

	Notes	Unrestricted funds (£)	Restricted income funds (£)	December 2021 (£)	December 2020 (£)
<b>Fixed assets</b>					
Tangible investments		-	10,854	10,854	13,776
Intangible investments					
<b>Total fixed assets</b>		<b>-</b>	<b>10,854</b>	<b>10,854</b>	<b>13,776</b>
<b>Current assets</b>					
Debtors and prepayments	5	46,022	14,949	60,971	74,953
Cash at bank and in hand		9,038	252,853	261,891	366,901
<b>Total current assets</b>		<b>55,060</b>	<b>267,802</b>	<b>322,862</b>	<b>441,854</b>
<b>Liabilities</b>					
Creditors: amounts falling due within one year	6	(13,486)	(16,765)	(30,251)	(35,634)
<b>Net current assets/(liabilities)</b>		<b>41,574</b>	<b>251,037</b>	<b>292,611</b>	<b>406,220</b>
<b>Total assets less current liabilities</b>		<b>41,574</b>	<b>261,891</b>	<b>303,465</b>	<b>419,996</b>
Creditors: amounts falling due after one year		-	-	-	-
Provisions for liabilities and charges		-	-	-	-
<b>Net assets</b>		<b>41,574</b>	<b>261,891</b>	<b>303,465</b>	<b>419,996</b>
<b>Funds of the charity</b>					
Unrestricted funds		41,574	-	41,574	63,848
Restricted income funds	7	-	261,891	261,891	356,148
Endowment funds		-	-	-	-
<b>Total funds</b>		<b>41,574</b>	<b>261,891</b>	<b>303,465</b>	<b>419,996</b>

The financial statements were approved and authorised for issue by the Trustees on 05/09/2022 and signed on their behalf by:



**Gurmeet Kaur**

Treasurer of the Board of Trustees

## BASIS OF PREPARATION

### Basis of preparation and accounting policies December 2021

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) – Charities SORP (FRS 102) and the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102). Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

### 1. ACCOUNTING POLICIES

*This list of accounting policies has been applied by the charity.*

Incoming Resources	
<b>Recognition of incoming resources</b>	These are included in the Statement of Financial Activities (SoFA) when: <ul style="list-style-type: none"> <li>- the charity becomes entitled to the resources;</li> <li>- the trustees are virtually certain they will receive the resources; and</li> <li>- the monetary value can be measured with sufficient reliability</li> </ul>
<b>Incoming resources with related expenditure</b>	Where incoming resources have related expenditure (as with fundraising or contract income) the incoming resources and related expenditure are reported gross in the SoFA.
<b>Grants and donations</b>	Grants and donations are only included in the SoFA when the charity has unconditional entitlement to the resources.
<b>Tax reclaims on donations and gifts</b>	Incoming resources from tax reclaims are included in the SoFA at the same time as the gift to which they relate.
<b>Contractual income and performance-related grants</b>	This is only included in the SoFA once the related goods or services have been delivered.
<b>Gifts in kind</b>	Gifts in kind are accounted for at a reasonable estimate of their value to the charity or the amount actually realised. Gifts in kind for sale or distribution are included in the accounts as gifts only when sold or distributed by the charity. Gifts in kind for use by the charity are included in the SoFA as incoming resources when receivable.
<b>Donated services and facilities</b>	These are only included in incoming resources (with an equivalent amount in resources expended) where the benefit to the charity is reasonably quantifiable, measurable and material. The value placed on these resources is the estimated value to the charity of the service or facility received.
<b>Volunteer help</b>	The value of any voluntary help received is not included in the accounts but is described in the trustees' annual report.
<b>Investment income</b>	This is included in the accounts when receivable.
<b>Investment gains and losses</b>	This includes any gain or loss on the sale of investments and any gain or loss resulting from revaluing investments to market value at the end of the year.

## Expenditure and Liabilities

<b>Liability recognition</b>	Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to pay out resources.
<b>Governance costs</b>	Include costs of the preparation and examination of statutory accounts, the costs of trustee meetings and cost of any legal advice to trustees on governance or constitutional matters.
<b>Grants with performance conditions</b>	Where the charity gives a grant with conditions for its payment being a specific level of service or output to be provided, such grants are only recognised in the SoFA once the recipient of the grant has provided the specified service or output.
<b>Grants payable without performance conditions</b>	These are only recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the charity.
<b>Support Costs</b>	Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, e.g. allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

## Assets

<b>Tangible fixed assets for use by charity</b>	These are capitalised if they can be used for more than one year, and cost at least £500. They are valued at cost or a reasonable value on receipt.
<b>Investments</b>	Investments quoted on a recognised stock exchange are valued at market value at the year-end. Other investment assets are included at trustees' best estimate of market value.
<b>Stocks and work in progress</b>	These are valued at the lower of cost or market value.

## 2. ANALYSIS OF INCOME AND ENDOWMENTS

Analysis		2021 (£)	2020 (£)
<b>Donations and Legacies</b>	Restricted income	418,022	431,947
	Unrestricted income	28,593	66,077
		446,615	498,024
<b>Other trading activities</b>		-	-
<b>Income from investments</b>	Bank interest	28	130
<b>Other income</b>		-	-
<b>Total income and endowments</b>		<b>446,643</b>	<b>498,154</b>

### 3. ANALYSIS OF RESOURCES EXPENDED

Analysis		2021 (£)	2020 (£)
<b>Costs of generating voluntary income</b>	Staff costs	54,109	53,351
	Support costs	18,738	9,057
		<b>72,847</b>	<b>62,408</b>
<b>Charitable activities</b>	Staff costs	126,254	124,386
	Support costs	43,721	21,132
	Direct project costs	315,013	277,688
		<b>484,988</b>	<b>423,206</b>
<b>Governance costs</b>	Independent examiner's fee	1,200	1,200
	Accounting advice & payroll services	4,139	964
	Trustees' expenses	-	-
	Trustee meeting	-	-
		<b>5,339</b>	<b>2,164</b>
<b>Total</b>		<b>563,174</b>	<b>487,778</b>

### 4. TANGIBLE FIXED ASSETS

	Freehold land and buildings (£)	Other land and buildings (£)	Plant, machinery and motor vehicles (£)	Fixtures, fittings and equipment (£)	Total (£)
<b>Cost</b>					
At 1 January 2021	-	-	14,608	-	14,608
Additions	-	-	-	-	-
Disposals	-	-	-	-	-
At 31 December 2021	-	-	14,608	-	14,608
<b>Depreciation</b>					
At 1 January 2021	-	-	832	-	832
Charge for the year	-	-	2,922	-	2,922
Disposals	-	-	-	-	-
At 31 December 2021	-	-	3,754	-	3,754
<b>Net Book Value</b>					
At 31 December 2021	-	-	10,854	-	10,854
At 1 January 2021	-	-	13,776	-	13,776

## 5. DEBTORS AND PREPAYMENTS

Analysis of debtors	Amounts falling due within one year (£)		Amounts falling due after more than one year (£)	
	2021	2020	2021	2020
Trade debtors	-	-	-	-
Amounts due from subsidiary and associated undertakings	3,241	10,958	-	-
Other debtors	57,730	63,995	-	-
Prepayments and accrued income	-	-	-	-
<b>Total</b>	<b>60,971</b>	<b>74,953</b>	-	-

## 6. CREDITORS AND ACCRUALS

Analysis of creditors	Amounts falling due within one year (£)		Amounts falling due after more than one year (£)	
	2021	2020	2021	2020
Loans and overdrafts	-	-	-	-
Trade creditors	1,200	1,200	-	-
Amounts due to subsidiary and associated undertakings	-	-	-	-
PAYE	2,265	4,374	-	-
Other creditors	617	783	-	-
Accruals and deferred income	26,169	29,277	-	-
<b>Total</b>	<b>30,251</b>	<b>35,634</b>	-	-

## 7. RESTRICTED FUNDS

Fund Name	Purpose and Restrictions
<b>Skin Cancer Prevention (Restricted)</b>	Skin cancer prevention services for people with albinism in Tanzania and Malawi
<b>Research (Restricted)</b>	Research into access to health for people with albinism in Tanzania
<b>Awareness Raising (Restricted)</b>	Creating and promoting positive imagery of people with albinism in Africa to raise awareness
<b>Vision Programme (Restricted)</b>	Vision services for people with albinism in Tanzania
<b>Umoja Children Centre</b>	Building of a centre for learning and healing for children with albinism in Tanzania
<b>Tailoring Project (UTC)</b>	Training, learning resources and tailored support to improve social inclusion for people with albinism in Tanzania

### Movement of major funds:

Fund names	Fund balances brought forward 1 January 2021 (£)	Incoming resources (£)	Outgoing resources (£)	Transfers (£)	Gains and losses (£)	Fund balances carried forward 31 December 2021 (£)
Skin Cancer Prevention	24,453	221,557	239,332	-	-	6,678
Research	19,987	-	19,987	-	-	-
Awareness Raising	58,643	-	3,585	-	-	55,058
Vision Programme	14,899	15,990	20,278	-	-	10,611
Umoja Children Centre	121,590	20,000	20,230	-	-	121,360
Malawi Operations	3,798	19,993	21,459	-	-	2,332
Victim Support	12,015	63,715	70,249	-	-	5,481
Core Costs	100,763	76,767	117,160	-	-	60,370
<b>Total Restricted Funds</b>	<b>356,148</b>	<b>418,022</b>	<b>512,279</b>	<b>-</b>	<b>-</b>	<b>261,891</b>

## 8. DETAILS OF CERTAIN ITEMS OF EXPENDITURE

Trustee expenses	2021 (£)	2020 (£)
Number of trustees who were paid expenses	0	1
Nature of the expenses		Bill payments
<b>Total amount paid (£)</b>	<b>-</b>	<b>357</b>

Fees for examination of the accounts	2021 (£)	2020 (£)
Independent examiner's or auditor's fees for reporting on the accounts	1,200	1,200
Other fees (for example: advice, consultancy, accountancy services) paid to the independent examiner or auditor	3,360	964

## 9. STAFF COSTS

Staff costs	2021 (£)	2020 (£)
Gross wages, salaries and benefits in kind	167,317	159,736
Employer's National Insurance costs	9,703	14,802
Pension costs	3,343	3,199
<b>Total staff costs</b>	<b>180,363</b>	<b>177,737</b>

Average number of full-time equivalent employees in the year	2021	2020
<i>The parts of the charity in which the employees work:</i>		
Fundraising	3	2
Charitable activities	3	3
Governance	1	1
Other	-	-
<b>Total</b>	<b>7</b>	<b>6</b>

## 10. GRANT-MAKING

Grants made to individuals/institutions	2021	2020
Purpose for which grants made	Amount (£)	Amount (£)
Cash support for a victim of attack in Zambia	551	827
<b>Total</b>	<b>551</b>	<b>827</b>

*There were no support costs associated with the charity's grant-making.*

## 11. TRANSACTIONS WITH RELATED PARTIES

Name of trustee or connected party	Legal authority (e.g. order, governing document)	Amounts paid or benefit value	
		2021 (£)	2020 (£)
Harry Freeland	Governing document	45,000	44,412

*There are no amounts owing to or from the charity's trustees or other related parties by the charity at the year end. All transactions undertaken by (or on behalf of) the charity in which a trustee or related party has a material interest have been disclosed in the Notes to the Accounts.*





**STANDING VOICE**

England & Wales - Charity number 1151250

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# Accounts

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# Trustees' Annual Report and Accounts

2020



## FOREWORD

2020 has been a challenging year for Standing Voice, people with albinism and our partners. Following the outbreak of COVID-19, the Governments of Tanzania and Malawi took steps to control the spread of the virus, banning public gatherings and closing educational institutions. These measures forced us to consider new approaches to our projects. As well as postponing non-urgent activities, we had to prepare for the possibility that health workers could be pulled away from delivering services to people with albinism to support the countries' responses to COVID-19. Furthermore, the pandemic meant people with albinism were more vulnerable than ever. To prepare us for all eventualities in April 2020 we developed an action plan, to help us mitigate the risk of infection while continuing to provide life-saving services and support to people with albinism.

As a result of this plan and through the determination of our staff and volunteers throughout the pandemic, we have managed to maintain the running of our programmes in Tanzania and Malawi with COVID-19 management measures in place. These have included social distancing, increased hygiene and sanitation, distribution of protective masks and reducing the number of patients attending each clinic by extending our services to a larger network of hospitals and health centres. We have integrated COVID-19 prevention into our health education sessions in hospitals, and developed an information leaflet on COVID-19 and albinism, which we've distributed to thousands of people with albinism. In addition, we have established a helpline so people with albinism and their caregivers can directly contact us with any concerns relating to their health, social situation or security.

Despite COVID-19, 2020 has seen the total number of people with albinism supported through our projects climb to over 7,500 across Tanzania and Malawi. Our work in dermatology has continued to see reductions in rates of skin cancer across both countries. We have trained 144 teachers to better support students with albinism in schools. We have delivered vocational training to 120 people, aimed at improving the socioeconomic security and physical and mental wellbeing of people with albinism and their families on Ukerewe Island in the following disciplines: tailoring, batik cloth-making, soap-making, music, art, drama, photography, and radio production. In March, we launched our latest advocacy and research initiative funded by the Wellcome Trust, which empowers people with albinism to engage with their own health data and explore creative responses to questions around albinism and skin cancer. We also began an exciting new trauma rehabilitation initiative for people with albinism funded by the United Nations Voluntary Fund for Victims of Torture. The project provides tailored material assistance and peer-to-peer counselling to people with albinism who have survived physical and psychological violence in Malawi.

Despite global travel restrictions, we have continued to advocate for the rights of people with albinism everywhere. In February we attended a historic meeting in Paris, where activists voted unanimously to form a global albinism alliance. The vote was an important step toward building solidarity among albinism groups around the world. In March, we returned to Geneva where we continued to utilise our special consultative status with the United Nations, to present our work in an address to the 43rd Session of the United Nations Human Rights Council. In June, we joined with albinism advocates and organisations around the world in a virtual conference to commemorate International Albinism Awareness Day.

With the prolonged restrictions on international travel and the majority of our staff working from home, the pandemic forced us to reevaluate how we work as an organisation. 2020 has been challenging, but also a time for reflection and positive internal growth. We have brought our work online, into shared workspaces across all our country teams. This has led to improvements in our systems and processes, aided better communication and made us into an ever more efficient team.

We extend our deepest thanks to our funders who have rallied around us in these testing times, and whose support has enabled us to keep saving lives. We are unable to mention everyone, but particular thanks this year go to: the Fondation Pierre Fabre, the Wellcome Trust, the Bilton Charitable Trust, the Tropical Health and Education Trust, the International Foundation for Dermatology and International League of Dermatological Societies, the United Nations Voluntary Fund for Victims of Torture, the Sir Halley Stewart Trust, the British and Foreign School Society and the James Tudor Foundation. Thanks also to Esther Ireland, the Wheeler family, the Edge and all Standing Voice Malawi supporters in Ireland. Our programmes would not operate without the support of our key partners: the Governments of Tanzania and Malawi, the Regional Dermatology Training Centre, the Tanzania Albinism Society, the Association of Persons with Albinism in Malawi, Beyond Suncare, Under the Same Sun and many others.

We give heartfelt thanks to our staff, advisory committees, volunteers, and local partners. Our work would not be possible without your strength and dedication. We are humbled by and grateful for the individuals who give their time and energy every day to help us improve the lives of people with albinism in Africa.

*Presented by*

*Sabine Zetteler*  
*Chair of the Board of Trustees*  
28/10/2021



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## LEGAL AND ADMINISTRATIVE INFORMATION

<i>Charity Name</i>	Standing Voice (UK)
<i>Charity No.</i>	No. 1151250 Charitable Incorporated Organisation (CIO)
<i>Postal Addresses</i>	Unit 34b Regent Studios 8 Andrews Road London E8 4QN  P.O. BOX 1902 Isamilo, Mwanza Tanzania
<i>Registered Addresses</i>	49 Newick Road London E5 0RP  P.O. BOX 180 Ukerewe Island, Mwanza Tanzania
<i>Board of Trustees</i>	Sabine Zetteler Gurmeet Kaur Harry Freeland Johanna Freeland
<i>Chair</i>	Sabine Zetteler
<i>Administration</i>	Harry Freeland, Jon Beale, Sam Clarke, Emily Spence Rosa Shindler, Nofal Ali Pasha, Bonface Massah Supported by a growing team of dedicated volunteers



A group of students with albinism receiving sunscreen at one of our clinics in Malawi  
 Photo credit: Owen Mchekeni

## REPORT OF THE TRUSTEES

### Constitution

Standing Voice (UK) was originally constituted under a Foundation Constitution that came into effect on 14th March 2013, on which date Standing Voice became registered as a Charitable Incorporated Organisation (CIO). The trustees are the only members of the CIO. If the CIO is wound up the members have no liability to contribute to its assets and no personal responsibility for settling its debts or liabilities.

### Board of Trustees

Trustees are appointed by existing trustees through an electoral process. There may be no fewer than three trustees at any one time on the Board of Trustees. There are four at present, and we aim to expand the Board further during 2021.

Standing Voice trustees hold quarterly board meetings. The board also addresses governance matters as and when necessary, through e-mail or other means as necessary.

Decisions are made either at a meeting of the charity trustees, or by resolution in writing or electronic form and agreed upon by all of the charity trustees. Agreements may comprise either a single document, or several documents containing the text of the resolution in like form to each of which one or more charity trustees has signified their agreement.

No decision shall be made at a trustee meeting unless a quorum is present at the time the decision is taken. The quorum is two charity trustees, or the number nearest to one third of the total number of charity trustees, whichever is greater, or such larger number as the charity trustees may decide from time to time.

In selecting trustees, consideration is given to the overall breadth of knowledge and experience required of the Board of Trustees. Candidates are typically interviewed by at least two existing trustees and nominations are then presented for approval to the board. Successful candidates, once appointed, receive appropriate training documentation about the roles and responsibilities of being a Standing Voice trustee.

### Organisational Structure

The trustees manage the affairs of the Charity on a voluntary basis and meet as necessary for this purpose, usually at least once a quarter. Harry Freeland is Standing Voice's Executive Director (since April 2014) and remains on the Board of Trustees. During the report period the charity had 6 paid staff members in the UK supported by a committed team of volunteers. Our global team comprises an additional 13 paid staff members based in Tanzania and 2 based in Malawi, as well as international consultants.

### Contributions of Volunteers

Standing Voice continues to work closely with skilled volunteers from a variety of professional and academic backgrounds who are committed to ending human rights abuses against people with albinism in Tanzania and Malawi.

Our Skin Cancer Prevention and Vision Programmes continue to be clinically delivered by Tanzanian and Malawian health professionals with the strategy and coordination support of the Standing Voice country teams. International researchers, professors, optometrists and dermatologists complemented our skilled Tanzanian and Malawian volunteers through providing guidance over the report period.

Our volunteer engagement development is resulting in a unique pool of expertise associated with and leveraged by Standing Voice's operations. We are currently formalising this provision of expertise by further developing our advisory committees, which inform our Board and staff team.

We are extremely grateful to all of our volunteers who continued to inform and shape our life-saving programmes this year.

## Our Purpose and Objectives

Standing Voice is an international NGO working in Tanzania and Malawi, with its headquarters in the United Kingdom. Standing Voice's primary objective is to end human rights violations against marginalised groups.

The objectives of the CIO are:

- I. the advancement of education;*
- II. the advancement of mental and physical health and the saving of lives;*
- III. the relief of poverty and the improvement of the conditions of life in socially and economically disadvantaged communities;*
- IV. the promotion of human rights and the promotion of equality and diversity, in particular but without limitation so as to relieve the needs of people who are socially excluded by assisting them to integrate into society.*

For the purposes of the above:

- I. "human rights" means human rights as defined in the Universal Declaration of Human Rights and subsequent United Nations conventions and declarations and will be promoted in particular by education about human rights and promoting respect for human rights;*
- II. people who are "socially excluded" means people who are excluded from society, or parts of society, as a result of one or more of the following factors: financial hardship; youth or old age; ill health (physical or mental); disability or medical condition; discrimination on the grounds of sex, race, ethnic origin, religion, colour, creed or sexuality; poor education or skills attainment.*

Standing Voice exists as a catalyst to amplify the voices of others. We aim to empower the people we work with to be the agents of change in their own lives, to build resilience and be healthy and self-sufficient. We currently focus on promoting the social inclusion of people with albinism in Tanzania and Malawi. Our team has over 14 years' experience working with this group. We are currently planning further expansion to other countries in Sub-Saharan Africa, through the replication of our programme models in collaboration with key partners.

People with albinism are commonly the victims of social exclusion in Sub-Saharan Africa, which has led to witchcraft-fuelled murder and marginalisation from health and education services. Our work with this group centres around several programmatic areas: Skin Cancer Prevention, Vision and Education, Trauma Recovery, Economic Empowerment and Advocacy. Through our core programmes our support is holistic and comprehensive to reflect the complex needs of people with albinism in their local context. We achieve our objectives by collaborating with a network of local stakeholders (such as government bodies, local community groups and international NGOs). All of our initiatives promote the social inclusion of people with albinism by:

- I. Advancing understanding and knowledge about albinism in wider society*
- II. Advocating for progressive state action*
- III. Developing the skills and expertise of both people with albinism and wider community members*
- IV. Increasing the positive impact of local service providers*
- V. Promoting the positive impact of local non-governmental stakeholders (civil society)*

The trustees of Standing Voice declare that they have had regard to both the Charity Commission guidance on public benefit and section 17(5) of the Charities Act 2011 on public benefit in carrying out their duties to achieve the charity's objectives.



A family with albinism on Ukerewe Island, Tanzania  
Photo credit: Imogen Freeland



We accordingly invested considerable time and resources in the development of a comprehensive action plan, which would prepare us for different eventualities, mitigating the risk of infection while continuing to provide life-saving services and support to people with albinism. Throughout the pandemic, we have managed to maintain our skin cancer services in Tanzania with COVID-19 management measures in place. These have included social distancing, increased hygiene and sanitation, and protective masks at places where gatherings are unavoidable. We have also supported tailors with albinism at our Umoja Training Centre to sew face masks, which have been distributed at clinics and directly in communities. We have integrated COVID-19 prevention into our health education sessions, and developed an information leaflet on COVID-19, sun protection, skin cancer and albinism, which we are distributing to thousands of people with albinism. In addition, we have established a helpline so people with albinism and their caregivers can directly contact us with any concerns relating to their health, social situation or security.

In Malawi, where government regulations have been stricter, we have been forced to adapt the SCPP delivery more significantly. Our team has travelled directly to patients' communities to distribute health packages containing sunscreen, protective masks, soap and sanitary pads, and an information leaflet about albinism, skin cancer, and COVID-19. We have reduced patients' travelling distances; limited the number of patients seen at one location; visited a wider network of health centres; and restricted clinical examinations only to high-risk patients. As in Tanzania, we have integrated COVID-19 prevention into our health education sessions and established a 24-hour helpline so patients and their caregivers can directly contact our team.

Despite the outbreak of COVID-19, 2020 has still seen our total number of registered patients climb to 6,549 in Tanzania. Of these, 3,693 patients receive our full clinical service, while 884 are remotely supported and 1,972 are served through sunscreen distribution only. Clinics have been delivered in 11 regions of Tanzania this year: Mwanza; Simiyu; Tabora; Geita; Singida; Dodoma; Shinyanga; Mara; Kagera; Kigoma; and Katavi. In Malawi, our registered patient total has reached 795 across five districts: Mangochi; Machinga; Nkhotakota; Salima and Lilongwe. The programme has also demonstrated extraordinary clinical impact in 2020, with reductions in rates of skin cancer and other malignant skin conditions across Tanzania and Malawi. In Tanzania, the average prevalence of harmful skin conditions has reduced by 6% in 2020 and the majority of patients requiring surgical intervention are now treated on-site by SV-trained dermatologists (rather than being referred to major hospitals). In situations where advanced cancer is diagnosed, Standing Voice has continued to coordinate referrals for life-saving treatment. 24 patients have been referred for further care through the SCPP this year. In both countries, compliance in the adoption of sun-protective behaviours has increased in 2020, growing to 87% in Tanzania and 76% in Malawi. As patients and their families absorb the messages and practices recommended in our educational sessions, we are beginning to see a population better equipped to protect its own welfare.

Where a patient's diagnosis is terminal, Standing Voice continues to provide comprehensive palliative care and psychosocial support for patients and their families. We have tragically lost 5 patients this year, while 5 continue to receive end-of-life support.

Standing Voice is committed to expanding the Skin Cancer Prevention Programme internationally, to make high-quality dermatological healthcare a continental reality for people with albinism across Africa. With the continued support of our patients and partners, we will work hard to realise this ambition in the months and years ahead.



A patient with albinism undergoing cryotherapy at one of our Skin Cancer Prevention clinics  
Photo credit: Owen Mchekeni

## VISION & EDUCATION

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In many African countries, the low vision that people with albinism experience as a result of their melanin deficiency is widely misunderstood and rarely accommodated by health and education providers. This damages the participation and performance of many children with albinism in school, and restricts opportunities for professional development and income generation among many adults with albinism.

Since 2014, Standing Voice has partnered with the Government of Tanzania to establish a nationwide network of clinics providing vision care and education to 3,882 people with albinism across 9 regions of Tanzania. We target schools to improve educational performance and promote inclusive teaching practice, and have trained hundreds of teachers as 'Vision Ambassadors' tasked with promoting the rights of students with albinism in schools. Sadly in 2020 large-scale clinics were untenable due to the outbreak of COVID-19 in Tanzania and across the globe. Subsequently, Standing Voice turned our attention to strengthening the quality and sustainability of the Vision Programme through the training of teachers. Many



A patient with albinism being examined by an optometrist at a Vision Event in Tanzania  
*Photo credit: Chihiro Tagata Fujii*

students with albinism in Tanzania underperform academically and grow up to be unskilled, unemployed and trapped in a structural cycle of poverty. By training teachers to nurture success and confidence among students with albinism at an early age, support networks are created for previously isolated individuals, creating role models and reversing stigma to ensure long-term integration and improved socio-economic security.

At the end of the year, and in partnership with the British and Foreign School Society, the Vision Programme team visited 15 schools across four regions of Tanzania to deliver training and provide remote support to 144 teachers. The programme benefitted 372 students with albinism across the 15 schools, with 86 students participating in focus group discussions to share their experiences and reflect on how their learning experience could be improved. In 2021, as a continuation of the partnership we hope to provide vision screening services to all students with albinism at the same 15 schools, and provide them with low vision assistive devices such as eye glasses, magnifiers and telescope monoculars.

Alongside our teacher training and school outreach in 2020, Standing Voice has also provided particularly close support for beneficiaries of our Education Scholarship Programme, which sponsors children and young adults with albinism to study at inclusive and high-achieving schools and universities. Following the closure of educational institutions due to COVID-19, our first priority was to ensure safe passage of these students to their home communities across Tanzania. This process was facilitated by our team, who maintained regular contact with all 20 students and regularly monitored their evolving needs and wellbeing during their time at home. Following the reopening of schools, all grantees have now safely returned to their respective schools to continue their education.

With the generous support of our funders and supporters, we hope to restart our Vision Programme clinical cycle next year to continue enhancing the lives of our patient network and improving the quality of education and further employment for students with albinism across Tanzania.

## **TRAUMA RECOVERY**

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In Malawi, 2020 has seen the launch of Standing Voice's new trauma rehabilitation initiative for people with albinism. Funded by the United Nations Voluntary Fund for Victims of Torture, the project provides tailored material assistance to people with albinism who have survived physical and psychological violence in Malawi. The project has begun with an extensive mapping exercise, with our team visiting vulnerable people with albinism to undertake needs assessments and define priorities for further support, which may include housing and home security measures, micro-finance and livelihood support, medical or school supplies, facilitation of trauma recovery or family reconciliation, and direct advocacy interventions in situations of risk, conflict or exclusion.

In response to the outbreak of COVID-19, interviewers have explored the impact of the pandemic on beneficiaries' needs and distributed information about the virus to beneficiaries and their families. Social distancing and enhanced sanitisation measures have been observed during the execution of needs assessments. The project is currently being piloted with 30 beneficiaries impacted by torture, but is due to be scaled up from 2021.

## ECONOMIC EMPOWERMENT

Economic security and access to livelihoods are a pivotal (and often overlooked) challenge facing people with albinism. Stigma and discrimination—exacerbated by high rates of skin cancer, and neglected vision needs in classrooms and workplaces—deprive many people with albinism of income-generating opportunities and pathways of professional development. In 2013, SV built and founded the Umoja Training Centre (UTC): a facility providing formal training initiatives to promote integration and shared prosperity for the community of Ukerewe Island on Lake Victoria. Built in collaboration with the Ukerewe Albinism Society, the UTC is a hub of community integration and a centre of healing for vulnerable people with albinism who have experienced discrimination and violence. Today the UTC delivers vocational training in a range of disciplines including tailoring, photography, radio, storytelling and performance, print-making, batik, soap-making and art.

The outbreak of COVID-19 has made it more difficult for training groups to convene at the UTC and strengthen their skills in chosen disciplines. Our implementation of social distancing measures at the UTC has limited the number of people able to use UTC facilities at the same time.

Despite these restrictions, 2020 has seen the UTC training groups achieve significant progress in honing their skills, marketing their products, and generating income. In response to the pandemic, the ‘Tunajitambua Tailors’ have produced 550 protective masks and 930 wide-brimmed hats for distribution in the care packages provided through our Skin Cancer Prevention Programme. The soap-making group has similarly produced handmade soap, which is being sold directly to the Ukerewe community from the UTC. In May 2020, the tailoring, soapmaking and radio broadcasting groups legally registered as district social development groups: a significant achievement that allows participants to operate in community settings and apply for interest-free support loans from the district council. The Young Reporters Group also broadcast 22 radio programmes across three local stations, airing their voices to thousands of people in the Lake Zone.

For two years, the UTC Community Library has brought together all parts of the community through their love of reading including children and adults, students and teachers, farmers, community activists, entrepreneurs, local leaders and politicians. In 2020, 3,780 adults and children visited the library (530 of whom were people with albinism) and 122 books were borrowed from a collection of over 10,000 books and newspapers, with 2,668 new books being added to the library this year.

A woman with albinism participates in a Standing Voice tailoring course  
Photo credit: Ebrahim Mirmalek



## ADVOCACY

Standing Voice creates platforms for people with albinism to speak out against violence and assert their own rights. We advocate locally and globally for the welfare of people with albinism through documentary films, academic publications, interdisciplinary symposia and stakeholder consultations. Our organisation has special consultative status with the United Nations Economic and Social Council, with annual accreditation to attend and participate in a wide programme of human rights events across the globe.

Despite severe travel restrictions across the globe, in 2020 we have continued to advocate for the rights of people with albinism everywhere. Prior to the outbreak of COVID-19, Standing Voice's Country Director for Malawi attended a historic meeting in Paris, where activists from six regions of the world voted unanimously to form a global albinism alliance. The vote was an important step toward building solidarity among albinism groups around the world. In March, we also returned to Geneva, where we presented our work in an address to the 43rd Session of the United Nations Human Rights Council. In June—despite a changing advocacy landscape in the wake of Covid-19—we joined with albinism advocates and organisations around the world in a virtual commemoration of International Albinism Awareness Day.

March this year also saw the launch of our latest local advocacy initiative funded by the Wellcome Trust. Using data generated by the Skin Cancer Prevention Programme, Standing Voice is working in partnership with the Bagamoyo Creative Arts Institute to empower people with albinism to engage with their own health data and explore creative responses to questions around albinism and skin cancer. The project began with training workshops in March, and, following a hiatus caused by COVID-19, resumed in November.

2020 also saw exciting steps toward the adoption and implementation of Tanzania's National Action Plan on Albinism. Created under the supervision of the Prime Minister's Office in the Ministry of Labour, Youth, Employment and Persons with Disabilities (PMO-LYED), the action plan was developed by a Coordinating Committee of which Standing Voice is the appointed Chair. Following extensive consultation and drafting throughout 2019, the plan was submitted to the Government of Tanzania for formal review in early 2020. The draft has since been assessed by the PMO-LYED Technical Committee, who have requested a final meeting with the Coordinating Committee to finalise the document and complete the government approval process. The plan provides the first official framework for monitoring and eradicating the discrimination and violence facing people with albinism in Tanzania. It will increase coordination between albinism organisations, and act as a crucial advocacy tool in holding the Government of Tanzania to account.



Inaugural meeting of the Global Albinism Alliance in Paris  
Photo credit: Global Albinism Alliance

## FUNDING MATTERS

### GRANT-MAKING POLICY

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The charity's policy is to make grants to collaborating organisations who are in need of funds to deliver a service in partnership with Standing Voice. On occasion the trustees may decide to give a grant to a beneficiary organisation that is not working in partnership with Standing Voice, but is working towards a shared objective of the charity.

In line with our current activities the organisation or service funded must promote the wellbeing and social inclusion of people with albinism in Africa through advancing health, education or community-based services.

All grants are awarded on the condition of robust accounting and financial reporting standards being adhered to by grant recipients.

### FUNDRAISING ACTIVITIES IN THE UK

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Standing Voice applies for grants from trust funds, grant-giving foundations and institutions, and corporate donors. Standing Voice also raises funds donated by individuals reached through direct approaches and by holding planned fundraising events and campaigns.

The charity's principal sources of funding during the year have consisted of grant funders and philanthropists donating to specific projects. Our plans for sponsored events have been restricted due to Covid-19.

We are proud to be funded by some of the most innovative grant funders who are active today including the Pierre Fabre Foundation, the Wellcome Trust, the International Foundation for Dermatology (IFD) and the United Nations Voluntary Fund for Victims of Torture (UNVFVT).

The trustees extend their sincere gratitude to all individuals and grant-givers who have donated to the organisation this year to ensure we continue our vital work.

### FINANCIAL PERFORMANCE

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Income during the period 1st January 2020 to 31st December 2020 amounted to £498,154 (1st April 2019-31st December 2019: £611,245). Voluntary income was £498,024 (December 2019 accounts: £606,393). Of the total income, £431,947 (December 2019 accounts: £511,022) was restricted and £66,207 (December 2019 accounts: £100,223) unrestricted. The restricted income consists of donated funds from grant funders and individuals. £356,148 (December 2019 accounts: £338,932) of restricted funding was carried forward. Unrestricted income was mainly from individual donations.

Expenditure amounted to £487,778 (December 2019 accounts: £515,490) of which £423,206 was project expenditure (December 2019 accounts: £463,495), £62,408 was fundraising expenditure (December 2019

accounts: £49,106) and £2,164 was governance costs (December 2019 accounts: £2,889). Of the total project expenditure, £414,731 was restricted expenditure (December 2019 accounts: £439,651) and £73,047 was unrestricted expenditure (December 2019 accounts: £75,839).

Standing Voice exercises a policy of setting aside 6 months of administration salaries and expenses as reserves to cover core costs in the event of the organisation encountering a period of reduced income. At the end of the financial year ending 31st December 2020 the charity carried forward a balance of £419,996 (December 2019 accounts: £409,620), and the organisation awaited funding responses from major grant funders. The trustees deemed reserve funds held to be sufficient, keeping in consideration the status of funding negotiations with key funders.

## **EXPENDITURE SUPPORTING KEY OBJECTIVES**

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The charity's expenditure this year has promoted the wellbeing and social inclusion of people with albinism as a marginalised group, and as such has been consistent with the charity's objectives.

People with albinism in Tanzania and Malawi have benefitted from vastly developed capacity; improved dermatological and low vision health services; increased access to education; and major advances in local and international awareness about societal reactions to albinism resulting from Standing Voice's project activity. Through our training and coordination of Tanzanian and Malawian professionals we are proud to be building a sustained, locally driven response to the multi-faceted challenges experienced by this group whilst fortifying positive perceptions of albinism in society. This has been achieved by pursuing our purpose and objectives as a charity.

Tragically, people with albinism in Tanzania and Malawi do however remain the target of violent attacks resulting from their ostracism in society. In addition to tackling the root causes of these atrocities, during this reporting period we have supported many individuals and communities who have endured trauma, including child attack survivors and family members of victims.

By investing in structured initiatives in the period between December 2019-December 2020, the charity has met its overarching objective of assisting those who are socially excluded by advancing their integration in society. Ultimately we have achieved this through programmes that engage wider society, and local professionals, in tangible action that elevates people with albinism in their community.

A mother and her baby with albinism at the Standing Voice Umoja Training Centre  
Photo credit: Innocent Mwandu



## GOVERNANCE AND RISK

### FUTURE PLANS OF THE CHARITY

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In 2021, we will expand the geographical reach of our Skin Cancer Prevention Programme in both Tanzania and Malawi. We will accelerate further our training of community leaders, teachers, health professionals, people with albinism and their families. Our work to build the capacity of our beneficiaries will also develop through increasing these individuals' access to information on their own welfare, and providing opportunities for them to communicate their own perspectives to key stakeholders who influence welfare outcomes. We will also continue adapting our dermatology services to allow for the inclusion of complimentary support at clinics, specifically psychosocial support and counselling. This will involve training a team of 'first responders' equipped to provide such services, led by Standing Voice staff members but also including other community stakeholders such as mothers of children with albinism, teachers, social workers and civil society leaders.

The expansion of our services in Malawi and Tanzania, both in terms of geographic scope and impact, will be combined with our sustained efforts to catalyse affirmative action from national governments. We will achieve this through our advocacy work within and beyond these countries of operation.

### RISK

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At present the primary risk to the internal management and administration of the charity is that of insufficient funding paired with pressures to meet growing challenges experienced by our beneficiary population.

We manage this risk through maintaining a varied portfolio of benefactor relationships, and the regular submission of new grant applications, combined with regular scrutinisation of our expenditure pipeline. The board holds regular financial planning discussions to assess the financial health of the organisation and plan accordingly. We consider the viability of programmatic action for the year considering both financial viability and Value for Money principles ('economy, efficiency and effectiveness').

Additionally, Standing Voice manages the risk of maladministration at the point of implementation through routine monitoring of our in-country teams in Tanzania and Malawi. Finance and activity reports are regularly scrutinised, and our UK trustees and management visit Standing Voice local offices and project areas. We hope to resume quarterly country visits following the easing of Covid-19 travel restrictions. Executive Management also monitors the flow of funds from the UK to our country offices through a two-step approval system involving the scrutiny and approval of all international transfers.

### RESPONSIBILITIES OF THE BOARD OF TRUSTEES

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The Trustees are responsible for managing the affairs of the CIO and may for that purpose exercise all the powers of the CIO. It is the duty of each charity trustee:

- A. *to exercise his or her powers and to perform his or her functions in his or her capacity as a trustee of the CIO in the way he or she decides in good faith would be most likely to further the purposes of the CIO; and*

*B. to exercise, in the performance of those functions, such care and skill as is reasonable in the circumstances having regard in particular to:*

- i) any special knowledge or experience that he or she has or holds himself or herself out as having; and,*
- ii) if he or she acts as a charity trustee of the CIO in the course of a business or profession, to any special knowledge or experience that it is reasonable to expect of a person acting in the course of that kind of business or profession.*

The charity Trustees are responsible for complying with the requirements of the Charities Act 2011 with regard to the keeping of accounting records, to the preparation and scrutiny of statements of account, and to the preparation of annual reports and returns for submission to the Charity Commission.

## **PUBLIC BENEFIT**

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In accordance with section 17 of the Charities Act 2011 the Trustees confirm that they have had regard to the Charity Commission's guidance in relation to public benefit. The Trustees have referred to the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning the charity's future activities. In particular, the Trustees have considered how planned activities will contribute to the aims and objectives they have set.

## **TRUSTEES' DECLARATION**

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So far as the Trustees are aware, there is no relevant information of which the charity independent examiner is unaware, and each Trustee has taken all the steps that he/she ought to have taken as a Trustee in order to make himself/herself aware of any relevant audit information and to establish that the charity's independent examiner is aware of that information.

Approved by the Board of Trustees and signed on its behalf by:

A handwritten signature in black ink, appearing to read 'Sabine Zetteler'.

**Sabine Zetteler**

Chair of the Board of Trustees

28/10/2021

One of our patients in consultation with a doctor in Tanzania  
Photo credit: Innocent Mwandu



## ACCOUNTS

### Independent Examiner's Report to the Trustees of Standing Voice

I report on the accounts of the charitable company for the year to 31st December 2020 which are set out on the following pages.

#### Respective responsibilities of trustees and examiner

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 114(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a member of ICAEW.

Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 145 of the 2011 Act;
- follow the procedure laid down in the General Directions given by the Charities Commission under section 145 (5)(b) of the 2011 Act; and
- state whether particular matters have come to my attention.

#### Basis of independent examiner's report

My examination was carried out in accordance with the general directions given by the Charities Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

#### Independent examiner's statement

In connection with my examination, no matter has come to my attention;

- 1) which gives me reasonable cause to believe that in any material respect the requirements:
  - to keep accounting records in accordance with the section 386 of the Companies Act 2016; and
  - to prepare accounts which accord with the accounting records comply with the accounting requirements of section 396 of the Companies Act 2016 and with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities (revised 2015) have not been met; or
- 2) to which, in my opinion, attention should be drawn to enable a proper understanding of the accounts to be reached.



**Martin R Vincent FCA**  
Astrum Accountants Ltd  
Maple House  
Cleeve  
Bristol  
BS49 4FS

## Statement of Financial Activities (SoFA)

Statement of Financial Activities (Incorporating an Income and Expenditure Account) for the period ended 31 December 2020:

	Notes	Unrestricted funds (£)	Restricted income funds (£)	Total 2020 (£)	Total 2019 (£)
<b>Income and endowments from:</b>					
Donations and legacies		66,077	431,947	498,024	606,393
Other trading activities		-	-	-	4,749
Income from investments		130	-	130	103
Income from charitable activities		-	-	-	-
Other income		-	-	-	-
<b>Total income and endowments</b>	<b>2</b>	<b>66,207</b>	<b>431,947</b>	<b>498,154</b>	<b>611,245</b>
<b>Expenditure on:</b>					
Raising funds		6,596	55,812	62,408	49,106
Charitable activities		64,287	358,919	423,206	463,495
Other expenditure		2,164	-	2,164	2,889
<b>Total expenditure</b>	<b>3</b>	<b>73,047</b>	<b>414,731</b>	<b>487,778</b>	<b>515,490</b>
<b>Net income/(expenditure) and net movement in funds for the year</b>		<b>-6,840</b>	<b>17,216</b>	<b>10,376</b>	<b>95,755</b>
<b>Net income/(expenditure) before other recognised gains/(losses)</b>		<b>-6,840</b>	<b>17,216</b>	<b>10,376</b>	<b>95,755</b>
<b>Other recognised gains/(losses)</b>					
Gains and losses on revaluation of fixed assets for charity's own use		-	-	-	-
Gains and losses on investment assets		-	-	-	-
<b>Net income/(expenditure) and movement in funds for the year</b>		<b>-6,840</b>	<b>17,216</b>	<b>10,376</b>	<b>95,755</b>
<b>Total funds brought forward</b>		<b>70,688</b>	<b>338,932</b>	<b>409,620</b>	<b>313,865</b>
<b>Total funds carried forward</b>		<b>63,848</b>	<b>356,148</b>	<b>419,996</b>	<b>409,620</b>

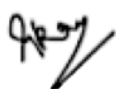
The Statement of Financial Activities includes all gains and losses recognised in the year. All the activities derive from continuing operations during the above periods.

## BALANCE SHEET

Balance Sheet as at 31 December 2020

	Notes	Unrestricted funds (£)	Restricted income funds (£)	Period to 31 December 2020 (£)	Period to 31 December 2019 (£)
<b>Fixed assets</b>					
Tangible investments		-	13,776	13,776	-
Intangible investments					
<b>Total fixed assets</b>		-	<b>13,776</b>	<b>13,776</b>	-
<b>Current assets</b>					
Debtors and prepayments	5	58,425	16,528	74,953	101,455
Cash at bank and in hand		21,711	345,190	366,901	336,421
<b>Total current assets</b>		<b>80,136</b>	<b>361,718</b>	<b>441,854</b>	<b>437,876</b>
<b>Liabilities</b>					
Creditors: amounts falling due within one year	6	(16,288)	(19,346)	(35,634)	(28,256)
<b>Net current assets/(liabilities)</b>		63,848	342,372	406,220	409,620
<b>Total assets less current liabilities</b>		<b>63,848</b>	<b>356,148</b>	<b>419,996</b>	<b>409,620</b>
Creditors: amounts falling due after one year		-	-	-	-
Provisions for liabilities and charges		-	-	-	-
<b>Net assets</b>		<b>63,848</b>	<b>356,148</b>	<b>419,996</b>	<b>409,620</b>
<b>Funds of the charity</b>					
Unrestricted funds		63,848		63,848	70,688
Restricted income funds	7		356,148	356,148	338,932
Endowment funds				-	-
<b>Total funds</b>		<b>63,848</b>	<b>356,148</b>	<b>419,996</b>	<b>409,620</b>

The financial statements were approved and authorised for issue by the Trustees on 28/10/2021 and signed on their behalf by:



**Gurmeet Kaur**

Treasurer of the Board of Trustees

## BASIS OF PREPARATION

Basis of preparation and accounting policies 1st January to 31st December 2020

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) – Charities SORP (FRS 102) and the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102). Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

### 1. ACCOUNTING POLICIES

*This list of accounting policies has been applied by the charity.*

Incoming Resources	
<b>Recognition of incoming resources</b>	These are included in the Statement of Financial Activities (SoFA) when: <ul style="list-style-type: none"> <li>- the charity becomes entitled to the resources;</li> <li>- the trustees are virtually certain they will receive the resources; and</li> <li>- the monetary value can be measured with sufficient reliability</li> </ul>
<b>Incoming resources with related expenditure</b>	Where incoming resources have related expenditure (as with fundraising or contract income) the incoming resources and related expenditure are reported gross in the SoFA.
<b>Grants and donations</b>	Grants and donations are only included in the SoFA when the charity has unconditional entitlement to the resources.
<b>Tax reclaims on donations and gifts</b>	Incoming resources from tax reclaims are included in the SoFA at the same time as the gift to which they relate.
<b>Contractual income and performance-related grants</b>	This is only included in the SoFA once the related goods or services have been delivered.
<b>Gifts in kind</b>	Gifts in kind are accounted for at a reasonable estimate of their value to the charity or the amount actually realised. Gifts in kind for sale or distribution are included in the accounts as gifts only when sold or distributed by the charity. Gifts in kind for use by the charity are included in the SoFA as incoming resources when receivable.
<b>Donated services and facilities</b>	These are only included in incoming resources (with an equivalent amount in resources expended) where the benefit to the charity is reasonably quantifiable, measurable and material. The value placed on these resources is the estimated value to the charity of the service or facility received.
<b>Volunteer help</b>	The value of any voluntary help received is not included in the accounts but is described in the trustees' annual report.
<b>Investment income</b>	This is included in the accounts when receivable.
<b>Investment gains and losses</b>	This includes any gain or loss on the sale of investments and any gain or loss resulting from revaluing investments to market value at the end of the year.

## Expenditure and Liabilities

<b>Liability recognition</b>	Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to pay out resources.
<b>Governance costs</b>	Include costs of the preparation and examination of statutory accounts, the costs of trustee meetings and cost of any legal advice to trustees on governance or constitutional matters.
<b>Grants with performance conditions</b>	Where the charity gives a grant with conditions for its payment being a specific level of service or output to be provided, such grants are only recognised in the SoFA once the recipient of the grant has provided the specified service or output.
<b>Grants payable without performance conditions</b>	These are only recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the charity.
<b>Support Costs</b>	Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, e.g. allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

## Assets

<b>Tangible fixed assets for use by charity</b>	These are capitalised if they can be used for more than one year, and cost at least £500. They are valued at cost or a reasonable value on receipt.
<b>Investments</b>	Investments quoted on a recognised stock exchange are valued at market value at the year-end. Other investment assets are included at trustees' best estimate of market value.
<b>Stocks and work in progress</b>	These are valued at the lower of cost or market value.

## 2. ANALYSIS OF INCOME AND ENDOWMENTS

Analysis		2020 (£)	2019 (£)
<b>Donations and Legacies</b>	Restricted income	431,947	511,022
	Unrestricted income	66,077	95,371
		498,024	606,393
<b>Other trading activities</b>		-	4,749
<b>Income from investments</b>	Bank interest	130	103
<b>Other income</b>		-	-
<b>Total income and endowments</b>		<b>498,154</b>	<b>611,245</b>

### 3. ANALYSIS OF RESOURCES EXPENDED

Analysis		2020 (£)	2019 (£)
<b>Costs of generating voluntary income</b>	Staff costs	53,351	37,400
	Support costs	9,057	11,706
		<b>62,408</b>	<b>49,106</b>
<b>Charitable activities</b>	Staff costs	124,386	87,267
	Support costs	21,132	28,277
	Direct project costs	277,688	347,951
		<b>423,206</b>	<b>463,495</b>
<b>Governance costs</b>	Independent examiner's fee	1,200	1,200
	Accounting advice & payroll services	964	876
	Trustees' expenses	-	300
	Trustee meeting	-	513
		<b>2,164</b>	<b>2,889</b>
<b>Total</b>		<b>487,778</b>	<b>515,490</b>

### 4. TANGIBLE FIXED ASSETS

	Freehold land and buildings (£)	Other land and buildings (£)	Plant, machinery and motor vehicles (£)	Fixtures, fittings and equipment (£)	Total (£)
<b>Cost</b>					
At 1 January 2020	-	-	-	-	-
Additions	-	-	14,608	-	14,608
Disposals	-	-	-	-	-
At 31 December 2020	-	-	14,608	-	14,608
<b>Depreciation</b>					
At 1 January 2020	-	-	-	-	-
Charge for the year	-	-	832	-	832
Disposals	-	-	-	-	-
At 31 December 2020	-	-	832	-	832
<b>Net Book Value</b>					
At 31 December 2020	-	-	13,776	-	13,776
At 1 January 2020	-	-	-	-	-

## 5. DEBTORS AND PREPAYMENTS

Analysis of debtors	Amounts falling due within one year (£)		Amounts falling due after more than one year (£)	
	2020	2019	2020	2019
Trade debtors	-	-	-	-
Amounts due from subsidiary and associated undertakings	10,958	60	-	-
Other debtors	63,995	93,154	-	-
Prepayments and accrued income		8,241	-	-
<b>Total</b>	<b>74,953</b>	<b>101,455</b>	<b>-</b>	<b>-</b>

## 6. CREDITORS AND ACCRUALS

Analysis of creditors	Amounts falling due within one year (£)		Amounts falling due after more than one year (£)	
	2020	2019	2020	2019
Loans and overdrafts	-	-	-	-
Trade creditors	-	-	-	-
Amounts due to subsidiary and associated undertakings	-	330	-	-
PAYE	-	-	-	-
Other creditors	5,157	6,989	-	-
Accruals and deferred income	30,477	20,937	-	-
<b>Total</b>	<b>35,634</b>	<b>28,256</b>	<b>-</b>	<b>-</b>

## 7. RESTRICTED FUNDS

Fund Name	Purpose and Restrictions
<b>Skin Cancer Prevention (Restricted)</b>	Skin cancer prevention services for people with albinism in Tanzania and Malawi
<b>Research (Restricted)</b>	Research into access to health for people with albinism in Tanzania
<b>Awareness Raising (Restricted)</b>	Creating and promoting positive imagery of people with albinism in Africa to raise awareness
<b>Vision Programme (Restricted)</b>	Vision services for people with albinism in Tanzania
<b>Umoja Children Centre</b>	Building of a centre for learning and healing for children with albinism in Tanzania
<b>Tailoring Project (UTC)</b>	Training, learning resources and tailored support to improve social inclusion for people with albinism in Tanzania

### Movement of major funds:

Fund names	Fund balances brought forward 1 January 2020 (£)	Incoming resources (£)	Outgoing resources (£)	Transfers (£)	Gains and losses (£)	Fund balances carried forward 31 December 2020 (£)
Skin Cancer Prevention	58,073	88,590	122,210	-	-	24,453
Research	33,617	-	13,630	-	-	19,987
Awareness Raising	71,812	-	13,169	-	-	58,643
Vision Programme	12,763	54,209	52,073	-	-	14,899
Umoja Children Centre	121,546	-	-44	-	-	121,590
Malawi Operations	201	18,069	14,472	-	-	3,798
Victim Support	22,127	-	10,112	-	-	12,015
Core Costs	18,793	271,079	189,109	-	-	100,763
<b>Total Restricted Funds</b>	<b>338,932</b>	<b>431,947</b>	<b>414,731</b>	<b>-</b>	<b>-</b>	<b>356,148</b>

## 8. DETAILS OF CERTAIN ITEMS OF EXPENDITURE

Trustee expenses	2020 (£)	2019 (£)
Number of trustees who were paid expenses	1	1
Nature of the expenses	Bill payments	Bill payments
<b>Total amount paid (£)</b>	<b>357</b>	<b>300</b>

Fees for examination of the accounts	2020 (£)	2019 (£)
Independent examiner's or auditor's fees for reporting on the accounts	1,200	1,200
Other fees (for example: advice, consultancy, accountancy services) paid to the independent examiner or auditor	964	876

## 9. STAFF COSTS

Staff costs	2020 (£)	2019 (£)
Gross wages, salaries and benefits in kind	159,736	112,829
Employer's National Insurance costs	14,802	10,325
Pension costs	3,199	2,257
<b>Total staff costs</b>	<b>177,737</b>	<b>125,411</b>

Average number of full-time equivalent employees in the year	2020 (£)	2019 (£)
<i>The parts of the charity in which the employees work:</i>		
Fundraising	2	1
Charitable activities	3	4
Governance	1	1
Other	-	-
<b>Total</b>	<b>6</b>	<b>6</b>

## 10. GRANT-MAKING

Grants made to individuals/institutions		
Purpose for which grants made	2020 Amount (£)	2019 Amount (£)
Health services / skin cancer prevention treatments and manufacturing of sunscreen	827	6,000
<b>Total</b>	<b>827</b>	<b>6,000</b>

*There were no support costs associated with the charity's grant-making.*

## 11. TRANSACTIONS WITH RELATED PARTIES

Name of trustee or connected party	Legal authority (e.g. order, governing document)	Amounts paid or benefit value	
		2020 (£)	2019 (£)
Harry Freeland	Governing document	44,412	33,750

*There are no amounts owing to or from the charity's trustees or other related parties by the charity at the year end. All transactions undertaken by (or on behalf of) the charity in which a trustee or related party has a material interest have been disclosed in the Notes to the Accounts.*

A group of patients waiting to be seen at a clinic in Tanzania  
Photo credit: Innocent Mwandu



